



50 years
focussed on Epilepsy



International Bureau for Epilepsy
1961 - 2011

ACKNOWLEDGEMENTS

I would like to thank first and foremost Harry Meinardi for his invaluable help in collecting information and getting the facts right.

Furthermore, I am grateful to Simon Shorvon for writing the Centenary History of ILAE, thus providing me with a wealth of historical facts that also concern IBE.

Finally, of course I am grateful to all editors of and contributors to the International Epilepsy News without whom much of the history of IBE would have been lost.

50 Years Focussed on Epilepsy

Looking Back and Gazing Forward

A condensed history of IBE's first 50 years

Compiled by Hanneke M de Boer

PREFACE

Epilepsy is responsible for high levels of suffering, affecting more than 50 million people worldwide, thus making it an important public health problem.

Epilepsy is the clearest example of a neurological disorder for which effective, cost-effective treatment is available. Recent studies in both the developing and the developed world show that, if properly treated, up to 70% of people with this condition could live productive and fulfilling lives. Yet, in developing countries, up to 90% or more of people with this condition are excluded from care and consequently remain in the shadows of the so-called treatment gap.

One reason for this exclusion is the social stigma attached to epilepsy. The stigma of epilepsy affects the education of children and young people and the employability of adults.

This is precisely the reason why the International Bureau for Epilepsy was founded in 1961, in Rome. From day one the Bureau thrived and soon could list a substantial number of achievements. In his presidential report to the General Assembly of the International League Against Epilepsy in Vienna (9th September 1965) during the 8th International Congress of Neurology, Francis L McNaughton mentioned the development of the Bureau in great detail:

"...One of the remarkable developments since the Rome meeting in 1961 has been the vigorous growth of the newly-organized International Bureau for Epilepsy under the direction of George Burden of London. The Bureau was established to meet the demand for international leadership in planning to meet the social needs of the epileptic patient. It is clear that up to 1961 the League itself had not provided sufficient leadership in this area".

Thus showing that, since its conception, both the Bureau and the League have complemented each other.

It all started in Rome and now we are going back to Rome. The International Bureau for Epilepsy will, very appropriately, celebrate its 50th anniversary in the city where it was conceived.

Much has changed since 1961; however, epilepsy still continues to take its toll, impairing the physical, psychological and social functioning of those

affected and equally causes serious psychological, social and economic consequences for their families. People with epilepsy, and sometimes their family members, are still stigmatized, generating a hidden burden which discourages them from seeking the diagnosis and care they require.

Thus we cannot relax and lean back, we need to move on, to continue the work that was initiated 50 years ago, in order to reach its goal, to improve the quality of life of all people with epilepsy and The Goal of the IBE is to improve the quality of life of all people with epilepsy and those who care for them.

Hanneke M de Boer

FOREWORD

Lighting a candle for epilepsy in Rome: the birth of IBE.

The first International Bureau for Epilepsy newsletter was circulated by George Burden early in 1963. This newsletter, in the form of a typed letter, gave details of all the activities that had been going on since IBE was founded roughly eighteen months earlier. This was a significant publication because it confirms that the Bureau was operational from 1961.

The creation of a sister international association to represent people with epilepsy and their families and carers had been suggested by leading members of the International League Against Epilepsy (ILAE) over the years since its foundation in 1909. Perhaps the most prominent of these was by the great American epileptologist, William G Lennox, in 1939.

However, it was only when the then head of the Argentinean ILAE chapter, Dr Abraham Mosovich, formally proposed the formation of the Bureau at the League's AGM in Rome in 1961 that IBE finally came into existence. This happened just two years after the League celebrated its 50th anniversary. This year, 2011, marks fifty years of achievement for IBE and, just as important, fifty years of continuing joint collaboration between IBE and ILAE. This special relationship was celebrated at ILAE's centenary celebrations in Budapest in 2009 and IBE's Golden Jubilee will likewise be jointly celebrated in Rome in August 2011.

George Burden from the British Epilepsy Association became the first IBE Secretary General at that historic meeting in Rome in 1961 and the emblem of the candle was also established at that time. It is fair to say that the candle continues to shine a light on all of the Bureau's activities across the years.

In 1966 Ellen Grass from the USA became IBE's first President and was to have a profound influence on the Bureau's activities for many years, as did George Burden. In 1968 Mrs Grass proposed the establishment of the Ambassador for Epilepsy award and it is testament to her enormous legacy that these awards continue to be treasured by all who are fortunate enough to receive one.

It is fair to say that much of the early work of IBE was concentrated in Europe and North America but great strides have been made in Asia Oceania, in

Latin America, in East Mediterranean and in Africa in recent years and this will, undoubtedly, gather pace in the next decades.

In fifty years time when the International Bureau for Epilepsy celebrates its centenary, there is no question but that all its members will honour Ms Hanneke de Boer for her work in writing the history of its first 50 years and making the job of writing the 100 year history so much easier. Thanks are due to Hanneke from all of us for doing such a magnificent job.

Mike Glynn
President IBE

INTRODUCTION

Fifty years of history definitely warrants writing it down, if only to learn from the past and not to forget.

Already in 1939 William Lennox, then ILAE President suggested, in a letter to his Secretary General HJ Schou that, as a special branch of the League, an association of laymen interested in epilepsy be formed. Still, Lennox's plea was not followed up until 1961. In that year IBE was conceived, as the name implies, as an office of ILAE concerned with the social aspects of epilepsy. From that year onward the Bureau started to function, it flourished and grew, in size and in the number of activities that were developed. The Bureau matured, it was the roaring 60's and emancipation did not stay unnoticed. In 1963 the development of an IBE constitution was initiated, which was finally adopted in 1965, as there had been no opportunity to obtain its formal adoption sooner. Following its adoption, IBE's first Executive Board was elected.

Collaboration with the League remained an important issue and this resulted in the adoption of revised constitutions of both IBE and ILAE, interlocking their Executive Committees in 1973. Furthermore, in 1974, a Declaration of Intent was adopted and preparations were made leading to one organisation. Epilepsy International was established as an agency, which was intended to merge or intertwine both organisations.

Co-operation intensified, although it was agreed that the Executive Committees would carefully examine the results of the joint activities. From then on joint meetings of the Executive Committees of IBE and ILAE took place regularly. It was hoped to achieve a complete merger of both organisations in 1981. However, in the end, this did not happen, as both lay members and professional chapters were reluctant to merge. In 1985 Epilepsy International was dissolved and IBE resumed its separate identity again on behalf of persons with epilepsy all over the world, especially covering the social aspects of epilepsy.

Collaboration with the League continued, as can be seen from joint activities such as the biennial International Epilepsy Congresses, the Global Campaign, EUCARE and more recently the Joint Taskforce for Advocacy in Europe. Collaboration between a patient/non-medical and a professional

organisation is unique in the world and does not stay unnoticed with policy makers.

Since 1985 IBE has expanded its activities and its membership progressively grew, which clearly can be seen by the appearance of an articles featured in the International Epilepsy News, clearly picturing a global organisation at work.

Writing up this history has been a joyous journey through time. A selection had to be made on what to report in this document and what to leave out. So much has happened and so many people were involved, anxious to make the Bureau concept work. This document proves it did! It contains the developments, the stumbling blocks and the perseverance of all those people working to improve the quality of life of people with epilepsy all over the world.

Hanneke M de Boer

THE CONCEPTION



George Burden, the first Secretary General of IBE

The history of the International Bureau for Epilepsy and the International League Against Epilepsy (ILAE), the professional organisation in the field of epilepsy are clearly intertwined. ILAE, of course, is the elder and was founded by physicians in 1909, but its original intent was clearly inclusive as Article IV of its first constitution clearly stipulates:

"Any person, who is interested, either scientifically or practically in the work of the League can become a member of the League"

In 1936 the wording of the statute regarding membership stated:

"The primary consideration for membership is an active interest in the objectives of the League. In countries which contain a branch organisation membership in this branch automatically carries membership in the International League"

Thus non-medical members could become members of the International League through membership of the national organisations¹. In 1939, during an ILAE meeting held in Copenhagen, William Lennox, then ILAE president suggested in a letter to the Secretary General, HJ Schou, that, as a special branch of the League, an Association of laypersons interested in epilepsy be formed. However, Lennox's suggestion was not pursued until 1961 – more than 20 years later.



*Any person, who is interested, either scientifically or practically in the work of the League can become a member of the League
ILAE Constitution 1909*

Harry Meinardi reported that during the 9th ILAE Meeting (1961) there was criticism from various sources that too little attention was being paid to the social and behavioural aspects of epilepsy². George Burden (General Secretary, British Epilepsy Association)

gave an account in *Epilepsia*³:

“September 1961 saw the Ninth ILAE Meeting in Rome. The British Epilepsy Association was permitted to hold a conference titled: ‘The Role of the Lay Organisation in the Treatment of Epilepsy’. At the end of the meeting Dr Mosovich proposed that an international bureau should be set up to:

- 1. Canalise all possible information about associations to help people with epilepsy and distribute this by means of a newsletter at a certain fixed period;*
- 2. Make information available on how to organise a laymen’s league and how this should be financed;*
- 3. Create an international film library about epilepsy;*
- 4. The emblem of the association should be the candle already adopted by the British Epilepsy Association and by associations in Australia, Canada, Sweden and New Zealand.”*

THE BEGINNING - 1961-1965

Thus, in 1961 IBE was conceived, as the name implies, as an office of ILAE concerned with the social aspects of epilepsy. From that year onwards the Bureau started to function and in 1963 George Burden announced the composition of the first board of directors². During this first period, several of the objectives suggested by Mosovich in 1961 were realised: the newsletter was created; the film library was established; information and assistance to form laypersons organisations was introduced. Enlightenment also became an important issue. George Burden was particularly concerned with the huge knowledge gap that was evident in developing countries. On three occasions he organised highly effective travelling workshops in easily accessible venues in the developing countries. While the workshops were successful, the concept was not unanimously supported by the epilepsy movement.

By 1965 the Bureau could list a substantial number of achievements: meetings, publication of reports on Epilepsy and Employment, Epilepsy and Education, The Adult Population of Epileptic Colonies and Epilepsy and Driving Licences.

In his presidential report to the General Assembly of the International League Against Epilepsy in Vienna (9th September 1965), during the 8th International Congress of Neurology, Francis L McNaughton mentioned the development of the Bureau in great detail⁴.

The International Bureau for Epilepsy Newsletter also reported on the upcoming meeting in Vienna: *“It has been suggested that the International*

Bureau should elect its committees of directors from amongst the membership, and that the International League should be asked to nominate scientific and medical advisers. It was also suggested that officers should be elected, such as chairman, treasurer, secretary”⁵

Formal Meeting of the International Bureau for Epilepsy: Vienna - 4th September 1965

This meeting was attended by representatives from five national societies, including nine members and several visitors. The following topics were discussed at this meeting:

Quadrennial Report: The meeting first adopted the Secretary General’s report for the four year period since the Bureau was established.

Constitution: A draft constitution had been prepared in 1963 but there had been no opportunity since for its formal adoption. Modifications had been suggested in Copenhagen and a further effort had been made to draft statutes which would be acceptable to government bodies.

Representatives of the League proposed that the Bureau should not have a separate constitution but rather, the constitution of the League should be modified to allow the Bureau to be an integral part of ILAE whilst maintaining a fair amount of autonomy in dealing with purely social affairs. Representa-



tives of the lay associations, however, did not think this would work and emphasised that some form of constitution was necessary for the clear-cut direction of the Bureau. This was also essential if government departments were to be asked to recognise the Bureau and, possibly, approve financial support. Even if the International League were to amend its constitution to allow a social service or layperson’s organisation to join the League, it was unlikely that patients’ groups would join the League. Professor Gastaut⁶, speaking for the International League, said:

“If the Bureau were allied to the League, but only concerned with social questions, no problems will arise. If, however, the Bureau were interested in questions which had a

medical aspect (e.g. the issue of driving licences) then the League needed some guarantees of the direction in which the Bureau was going. The League and the Bureau are linked together which involves mutual responsibilities”.

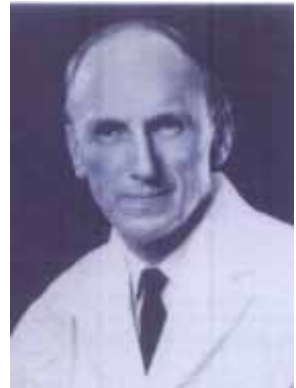
He therefore suggested that, if the Bureau were to have its own constitution, there were three conditions for the League to continue and participate in the activities of the Bureau:

- a. The direction of the Bureau should be in the hands of a small committee, i.e. 5 persons;
- b. A medical advisory body (possibly the officers of the International League) should be nominated with the approval of the League;
- c. All decisions concerning medical questions should be referred to the medical board

It was decided to put these questions to member organisations for their decision.

1. should IBE have an independent constitution incorporating the three points above, or
2. should IBE not have a formal constitution

Until this moment in time IBE had only met once every four years, similar to ILAE. However, social problems and the ‘tilling of a new field’ called for more frequent meetings.



Francis McNaughton

Finances: The finances of the Bureau were also discussed and it was agreed to set minimum annual subscriptions (annual dues).

Symposium on Driving Licences - Vienna, Austria - September 1965

Held under the auspices of the International Bureau for Epilepsy and the International League Against Epilepsy and chaired by Dr Francis McNaughton⁷:

General Meeting -Wiesbaden, 15th September 1966

The purpose of this meeting, held during the 10th World Congress of the International Society for Rehabilitation of the Disabled was to agree a Constitution for the Bureau. During the congress the Bureau joined the Deutsche Sektion der Internationale Liga gegen Epilepsie in mounting an exhibition. A meeting on “Rehabilitation of Epileptics* and Insurance” was also arranged.

**At that time the word “Epileptic” was commonly accepted in referring to a person with epilepsy.*

PERIOD: 1966 - 1973

The newsletter following the Wiesbaden meeting opened with a Presidential Message by the newly elected IBE president: Mrs Ellen Grass



Mrs Ellen Grass, first
IBE President

" I have assumed the task of guiding Bureau in these early years with great misgivings as to my worthiness to serve. I am consoled, however, by the zeal and enormous abilities of the officers who have graciously consented to work by my side. We shall count heavily on the guidance of the International League as well.

We welcome your suggestions on programmes and procedures, and our sincere wish is that you will communicate with us fully and often.

With warm greetings,

*Ellen Grass
President"*

The Constitution had finally been agreed upon and an Executive Board elected. It provided for a Council representing corporate members (a national or state organisation or an institution); co-operation with ILAE; the establishment of a Medical Advisory Board from ILAE officers; and for representation on the Council by the ILAE President and the ILAE Secretary General.

The International Epilepsy Newsletter reported: "Perhaps the most important event in 1966 was the meeting convened at the time of the 8th Congress of the International Society of the Disabled in Wiesbaden, Germany. Here, witnessed by 15 representatives from 10 different national associations, the first Constitution of the Bureau was formally adopted. The Bureau had now become a legal entity and could look forward to recognition in the countries who supported it".

International Epilepsy Newsletter, No. 18, July 1969

Collaboration with the League remained an important issue and, following the adoption of the Constitution, the Secretary General (George Burden) visited the ILAE president (Dr Lorentz de Haas, Netherlands) to discuss ways in which IBE might work more closely with the League. They discussed the establishment of a so-called "European Institute and Reviews of Social and Medical Services for the Epileptic Patient".

European Institute

It was thought that such 'Institutes' might be held annually in different European locations with mixed programmes, including a medical and scientific element and social element focussing on a study of a particular social topic. The European Institute lost its name over the course of years, but developed into successful symposia and, subsequently, into international epilepsy congresses that continued the medical/scientific and social topics format.

Driving

Driving remained an important topic for the Bureau and Dr Mogens Lund summarised the problem of epilepsy and driving licences in the newsletter following his attendance at a Congress of the International Association for Accident and Traffic Medicine⁸:

"A driving licence is of real importance to one third of epileptic men and a few percent of women in Denmark, and is very often of occupational importance. With modern treatment more than one third of patients can be seizure free. The prognostic estimation of a neurologist in cases of epilepsy is very safe. Research findings show that only 3 out of ten thousand police reported accidents are caused by an epileptic attack behind the wheel. All these studies, however, are open to criticism from a statistical point of view. We are still in need of epidemiological studies."*

* In the 60's only one third of people with epilepsy would be seizure free with medication as opposed to two thirds today.



Reviews of Social and Medical Services for the Epileptic Patient

Dr Lorentz de Haas, in his role as editor-in-chief of *'Epilepsia'*, the journal of the International League Against Epilepsy, was interested in receiving further studies of the medical and social services being provided for patients with epilepsy in different countries for which the Bureau might provide a basic programme⁸.

Ambassador for Epilepsy Award

In July 1967 (Newsletter no. 12) a proposal by the IBE President, Mrs Ellen Grass to introduce an Ambassador for Epilepsy Award was mentioned.

Public Relations

IBE continued to be engaged in developing new contacts and maintaining and improving existing contacts. Reports that might be relevant for the epilepsy world were published and IBE organised its first film festival together with Les Amis de la Ligue Belge contre l'Épilepsie – its chapter in Belgium, in November 1969.

Membership

In 1963, 19 national Leagues Against Epilepsy were registered as members of ILAE, but only four paid money to the cash-account of IBE. However, there was agreement that the donation of US\$600 by ILAE should be considered a summated membership contribution of all its 19 associated members. Members would receive the Journal of the British Epilepsy Association. It is not revealed which were considered to be IBE members or how membership could be obtained⁹. The Bureau continued to grow. Members were divided into National and State Associations, Institutions and Individual members. In the Constitution, however, only 2 categories of members were mentioned:



Membership Categories

- (i) Corporate membership shall be open to national and state organisations, whether lay or medical, especially interested in the welfare of people suffering from epilepsy, or institutions concerned with the care of epileptics.
- (ii) Non-Corporate Membership shall be comprised of individual members in various parts of the world interested in epilepsy

While the Constitution did not include membership criteria, it did stipulate how a member could resign - although it remains unclear as to how this rule was applied.

Annual subscriptions were first mentioned after the meeting in Vienna. (1965). In 1967 the subscriptions for National Associations doubled. The newsletter reported: *"We are very pleased to learn that the League has agreed to pay an annual subscription to the Bureau of 500 dollars"*.

IBE Membership dues in the early years

	Sept 1965	March 1967	Jan 1970
National Associations	£20.00	£40.00	£50.00
State associations	£10.00	£10.00	£20.00
Hospitals, Institutions, etc.	£5.00	£5.00	£10.00
Individual Members	£2.00	£2.00	£2.00

The IE Newsletter also reported that it was agreed that, by virtue of the contribution made by the League to the Bureau, all League members automatically became members of the Bureau. In an effort to make money, the announcement continued: *"... Any members of the League can, of course, make a voluntary contribution to the Bureau if they so wish, and any associations in the field of epilepsy not affiliated to the League can become Bureau members through an ordinary application"*. However, it did not mention what an "ordinary application" entailed.



PERIOD: 1973 - 1985

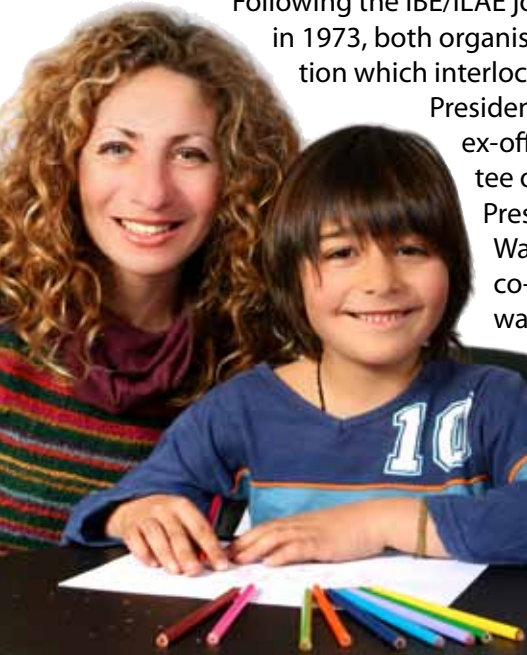
During its Council meeting, 5th September 1971 (Amsterdam), and during a meeting of Bureau and League officers, the procedure for bringing the IBE constitution closer to the ILAE constitution was discussed. Constitutions for both organisations were drafted in 1972, for submission to ILAE branches and national and state IBE members, in order to be formally presented to the IBE and ILAE quadrennial meetings in September 1973. The idea of an International Epilepsy Foundation was suggested to support both ILAE and IBE¹¹. Dr Mogens Lund (Vice-President IBE) responded to this idea most favourably¹². The officers of both organisations already consulted regularly, whilst ILAE had always provided professional advisors to IBE.

On the same issue, IBE's president, Mrs Ellen Grass reported during the IBE General Meeting (Barcelona, Spain, 1973) of the *"steady orderly growth and development of IBE since its founding"*. Mrs Grass specifically mentioned the contributions of *"helpful colleagues in the International League who played significant roles in bringing this about"*.

She also mentioned that the time had come to provide for rotation of officers and proposed *"to appoint a nominating committee from the council at the Barcelona meeting to propose suggestions for a president-elect to the Council, to be voted upon at a meeting in 1975. This would permit two years of overlap during which the duties of the presidency could be shared"*.

Following the IBE/ILAE joint international congress in Barcelona in 1973, both organisations adopted a revised constitution which interlocked their Executive Committees. The

President and Secretary General of IBE became ex-officio members of the Executive Committee of ILAE and vice versa¹. In June 1974, the Presidents and Secretaries General met in Washington to discuss a policy for further co-operation. The result of this meeting was the ***Declaration of Intent***, which was unanimously adopted by both Executive Committees at their meetings in Brussels, Belgium, September 1974. The consensus was that the Declaration would advance the purposes of each organisation. It was agreed that



Declaration of Intent

The fight against epilepsy requires the maximum utilisation of all the available resources in manpower and in financial support. We therefore recommend:

- 1. That the two organisations, while retaining their separate identity, aims and objectives, should work together under the name of Epilepsy International*
- 2. That there should be joint use of office facilities in London and Washington. In this connection, a volunteer is working for both organisations in Washington D.C.*
- 3. That notepaper with a letterhead indicating joint activity of the two organisations should be designed.*
- 4. That appeals for financial assistance should be made in the name of Epilepsy International, but for stipulated use.*
- 5. That the Newsletter be published by Epilepsy International, for the time being at the London office*
- 6. That a scheme for shared individual membership be prepared for discussion*
- 7. That these proposals be implemented from January 1st 1975, and that a programme review be made to our meeting in June 1975.*

David O Daly, President

Ellen R Grass, President

J Kiffin Penry, Secretary-General

George S Burden, Secretary General

International League Against Epilepsy

International Bureau for Epilepsy

at their meeting planned for June, 1975 (Berlin, Germany) the Executive Committees would carefully examine the results of their joint activities¹⁴.

In December 1974, the IBE Newsletter launched the new concept, "Epilepsy International" (EI) was intended to merge or intertwine both organisations¹. Further steps towards bringing the work of ILAE and the IBE together were taken during a meeting of both Secretaries General in London (January 1975).

In the September issue it was reported that Mrs Grass, IBE's President, indicated that she wished to step down as President in 1977. A nominating committee was charged with the task of organising a ballot for a President Elect as proposed by her in 1973. A short list of three names was prepared and ballot papers sent out. Over half of the ballot papers were returned in favour of Dr Mogens Lund, who was duly agreed by the Board of Directors. Dr Lund accepted the position.

Since the adoption of the Declaration of Intent in 1974, preparations had been made to establish one joint organisation. It had been hoped to achieve this by the time of the General Meeting in Amsterdam, 1977. This proved not to be possible and IBE and ILAE had to elect their own executives for another four year term. During the meeting of the Executive Committee of the International Bureau for Epilepsy, also held in Amsterdam, the nominating committee presented a slate of officers for election. During the General Meeting the new officers were elected in accordance with the slate. A resolution was accepted that the Board of Directors^s would authorise the Executive Committee to conduct such joint operations with ILAE as deemed reasonable to them, consistent with previous understandings, but that such joint operations would not involve loss of separate legal entities for the two organisations. From then on regular joint meetings of the Executive Committees of IBE and ILAE were held.

In March 1979 the Epilepsy International Committee met again for its, now called, semi-annual meeting in Heemstede, the Netherlands. The precarious financial position was a major item for discussion. The number of staff had to be reduced.

As promised support for the Epilepsy International News was received, further steps could be made to make the newsletter available to as many IBE/ILAE chapter members as possible. In order to cover postage and

costs for its production, an annual subscription equivalent to 8 Swiss francs was charged.

Proposals for IBE and ILAE membership criteria were being prepared to be discussed in Copenhagen, Denmark, during the 12th International Epilepsy International Symposium in order to achieve the complete merger of both organisations. In Kyoto (1981), following the Epilepsy International Congress and the various IBE/ILAE and Epilepsy International business meetings, Francesco Castellano, then Chairman of Epilepsy International reported in the EI News¹⁵:



Francesco Castellano
IBE President 1981-1985

§ Board of Directors 1977-1981

Category A (National Associations)	24 places
Category B (State Associations & Institutions)	16 places
Category C (Representing individual members)	12 places

“During the separate IBE and ILAE General Assemblies it became clear that, although some chapters of both organisations were interested in membership of Epilepsy International, in order to continue and expand the work of both organisations there was a need for further work by the EI Board of Directors and communications to the chapters to resolve questions and concerns.”

Despite this message Castellano remained positive about the potential advantages and possibilities that would be made possible if the organisations were merged.

Dr Mogens Dam, ILAE President and EI Vice Chairman stated that IBE and ILAE had been working towards a merger for many years. In Kyoto a vote was taken at the ILAE General Assembly, and the proposal was voted down. To Dam it was evident that both organisations should join forces in the fight against epilepsy on an international level¹⁶. During the ILAE Executive Committee the merger was again discussed. Some felt that ILAE was being directed by EI regulations, for which ILAE had never voted and that EI was directing the course of the organisation rather than acting as its agent.

As the years passed, the Epilepsy International News continued to report on activities being planned for the future, such as the development of an EI Comprehensive Plan 1982-1986. This plan was approved by the Executive Committee of EI at its meeting in Hamburg, Germany in April 1985, although the reluctance of both lay and professional chapters to the merger was mentioned¹⁷.

The General Assemblies of IBE and ILAE, and the election of the Executive Committees for 1981-1985, were held at the time of the Epilepsy International Congress in Kyoto (1981). In accordance with the EI Bylaws those elected to the committees made up the Board of Directors of Epilepsy International, which would continue to serve as an agent of the League and the Bureau.

Both Presidents, Francesco Castellano (IBE) and Mogens Dam (ILAE),



International Epilepsy News - June 1997

reported in *Epilepsy International News* "Towards a world without the suffering of Epilepsy"¹⁸.

The IBE Executive Committee met again in Hot Springs, Virginia, USA in October 1984 in order to plan IBE's future and to review IBE programmes, which had been managed through Epilepsy International since 1978. The relationship with ILAE was discussed in great detail. The IBE programmes had enhanced and expanded during the time when a merger between IBE and ILAE was considered possible. Some areas of future close cooperation with the League would include fundraising, the biennial congresses, recognition of Ambassadors for Epilepsy and efforts in developing countries¹⁹.

In Hamburg, September 1985, new IBE and ILAE Executive Committees were elected during their respective General Assemblies for the term 1985-1989. Epilepsy International was dissolved and EI commissions were divided or put under the jurisdiction of IBE (Drivers licences) or ILAE (Developing Countries). *Epilepsy International News* was returned to IBE and its name changed to "*International Epilepsy News*".

A significant number of activities were developed during this period:

Immigration regulations

A survey on conditions under which people with epilepsy could visit, work or become permanent residents in a country other than their own, was undertaken by the International Bureau in 1964 and repeated in 1973²⁰.



IBE Travelling Workshops

From visits to Africa made by the Secretary General, George Burden (1964) it had become apparent that the availability of medication was of the utmost importance. In response, the Bureau, encouraged by the International League organised a more extended tour of seminars and workshops²¹.

Driving Licences in the European Economic Community (Forerunner of the European Union)

ILAE and IBE representatives met with a representative of the Direction Generale des Transports in the EEC to discuss proposals for harmonising regulations concerning granting driving licences in the EEC member countries. The Epilepsy International Committee on Drivers Licensing drew up a report following its review of drivers licensing requirements in countries around the world (1981)²².

International Glossary of Anticonvulsants

At the council meeting in 1968, Dr Jerome Merlis (ILAE President) reported that preliminary work on an International Glossary of Anticonvulsants had commenced when it became apparent that worldwide confusion existed about the nomenclature of drugs used in the therapy of epilepsy²³. No mention was made of this glossary until 1970, when George Burden reported to the council meeting in Elsinore, Denmark, that almost 4,000 copies of the Glossary had been distributed²⁴. In 1973 an extensive report on the Glossary appeared, describing the objectives of the Anticonvulsant Glossary Committee and its objectives²⁵. A third edition of the Glossary was completed in 1977 under the auspices of Epilepsy International.

Workshop on the psychosocial assessment of persons with epilepsy (WOPSASSEPY I)

This 2-day meeting was held in the Netherlands in November 1979 with the aim to discuss the psychosocial assessment of people with epilepsy and proceedings published under the title *"Epilepsy and Behaviour"*²⁶. Further workshops were held, with the themes *"Workshops on Epilepsy"*, *"Pregnancy and the Child"* and on *"Epilepsy and Memory Function"*. Additional workshops were in preparatory stages of development²⁷.

Workshop on the evaluation of the expectations of people with epilepsy

Under the auspices of EI this 3-day workshop was held in Lille (France) 2-4 June 1983. Issues such as the expectations of people with epilepsy and their families; attitudes of the various specialists concerning these expectations;

how to meet these expectations; the role of authorities at local, national and international level, etc. To tackle these problems this workshop brought together professionals from the social and medical field and people with epilepsy and their families from a number of countries. A set of recommendations was developed for the Board of Directors to be discussed during an international “*Public Education Exchange*” to be held in association with the 1985 Epilepsy International Symposium, Hamburg, Germany.

Committee on Chapter Development – Social Aspects (1980).

This EI Committee produced an information pack which included guidance on drafting a Constitution and Bylaws and suggested text, advice on establishing chapters interested in the Social Aspects of Epilepsy.

Committee on Library Development (1980)

The EI Executive Committee had recommended the appointment of such a Committee. Its first task was to assemble and review educational materials on epilepsy which had been produced by chapters of IBE and ILAE as it was

one of EI’s objectives to select literature which could be reproduced in other languages.

International Meeting, Barcelona

In 1973, the International Congress of Neurology, the International League Against Epilepsy and International Bureau met for their respective meetings.

Fundraising Celebrity Football Match

Over 4,000 fans attended an EI sponsored celebrity football match held at Florida State University, Tallahassee, Florida, USA in April 1981, organised by Patsy McCall-Castellano to benefit Epilepsy International programmes. During the weeks preceding the game, television and radio programmes, newspaper articles and public announcements provided information on football history and enhanced public knowledge on epilepsy.





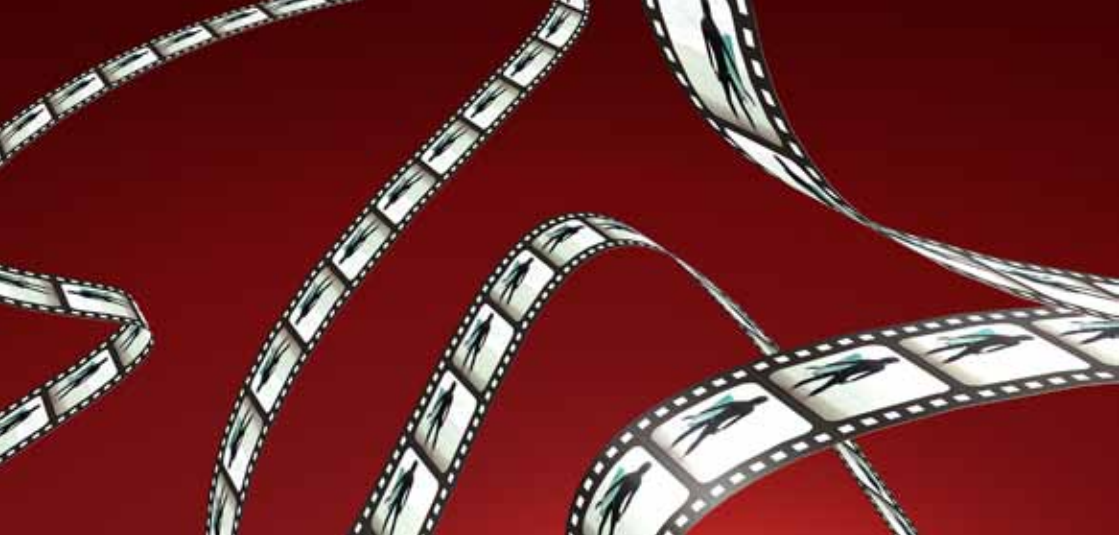
International Symposia/Congresses

International Symposia/Congresses were organised on a yearly basis until and including 1983, after which the congresses took place biennially.

- 6th International Symposium: Ottignie, Belgium, September, 1974
- 7th International Symposium: Berlin, June, 1975.
- 8th International Symposium In Dublin, September 1976
- 9th Symposium of the International Bureau for Epilepsy and 13th Congress of the International League Against Epilepsy, Amsterdam, September 1977
- International Symposium, Vancouver, September 1978
- 11th Epilepsy International Symposium, Florence, October 1979
- 12th Epilepsy International Symposium, Copenhagen, September 1980
- 13th Epilepsy International Symposium, Kyoto, September 1981
- 14th Epilepsy International Symposium, London, 1982
- 15th Epilepsy International Symposium, Washington DC, September 1983
- 16th Epilepsy International Symposium, Hamburg, September 1985

Public Education Seminar during the Hamburg Congress 1985

The means of overcoming the negative attitudes of the general public were explored during this first International Public Education Seminar. Its aims were: to increase the level of expertise in public education worldwide, to offer an opportunity to exchange ideas about methods of promoting public education, and to provide a forum for examining educational campaigns.



1st Audiovisual Festival during Hamburg Congress 1985

The festival attracted 163 entries from 21 countries, which were assessed by an international panel of jurors consisting of Ann Sherer (USA), Mr. Citron (USA), Tim Betts (UK), Dr. Wannamaker (USA), Nimal Senanayake (Sri Lanka), Mrs Borregaard (Netherlands), Patsy Castellano (USA), Jane Treiman (USA), Arthur Sonnen (Netherlands), Hermann Stefan (Germany) and Colin Binnie (Netherlands). The materials submitted gave a 50-year overview covering the period 1935-1985.

In conjunction with the festival, an international catalogue on epilepsy related films, videotapes and slides, 1985, titled: *'Epilepsy in Focus 1985'*, was published.

Prize winners Gold award (1st prize) 1st Audiovisual Festival:

Professional section

National Society for Epilepsy UK

General Audience section

Public Awareness

Epilepsy Federation of Greater Virginia, USA

Patient Education

Epilepsy Foundation of America, USA

Public Service Announcement

Epilepsy Foundation of America, USA

Drama/Entertainment

Nimal Senanayake, Sri Lanka

Membership

Membership was discussed by the IBE/ILAE Executive Committees during their meeting in Amsterdam, the Netherlands, September 1977. It was recommended that a definition for the term 'lay member' be developed in order that all professions might clearly recognise their role as members of

the proposed Epilepsy International. In order to clarify membership rules, a Membership Committee was appointed, consisting of both Presidents - Harry Meinardi (IBE) and J Kiffin Penry (ILAE) and Secretaries General - Richard Grant (IBE) and Francisco Rubio Donnadiou (ILAE). During its discussions one point in the debate was the possible need to distinguish between professional and lay members. This was based on historical roots, when distinction was made between medical and lay people. In the meantime, the fact that the field of epilepsy was covered by several disciplines had been recognised and had, for instance, already been included in the ILAE constitution²⁸. A short announcement regarding membership appeared in the Epilepsy International Newsletter later in 1977, showing the progress made in the discussions.

There was no further news on this issue until 1984, when it had become clear that the merger between IBE and ILAE was no longer being considered.

A Dues Assessment Committee had been appointed to revise the existing structure and to develop a new dues structure in time for the IBE General Assembly in 1985.



PERIOD: 1985 - 2011

After the dissolution of Epilepsy International, IBE resumed its separate identity as an organisation working on behalf of persons with epilepsy at international level, with particular focus on the social aspects of epilepsy. The close working relationship with ILAE continued, which was evident from the fact that two members of the Executive Committee of the League were voting members in the Bureau's Executive and vice versa.

In April 1986 the first of a series of meetings of the IBE and ILAE Executive Committees took place in Switzerland. These meetings consisted of separate meetings of each executive committee, a joint meeting of both committees and a half day meeting with representatives of the sponsor company of these meetings: Ciba Geigy.



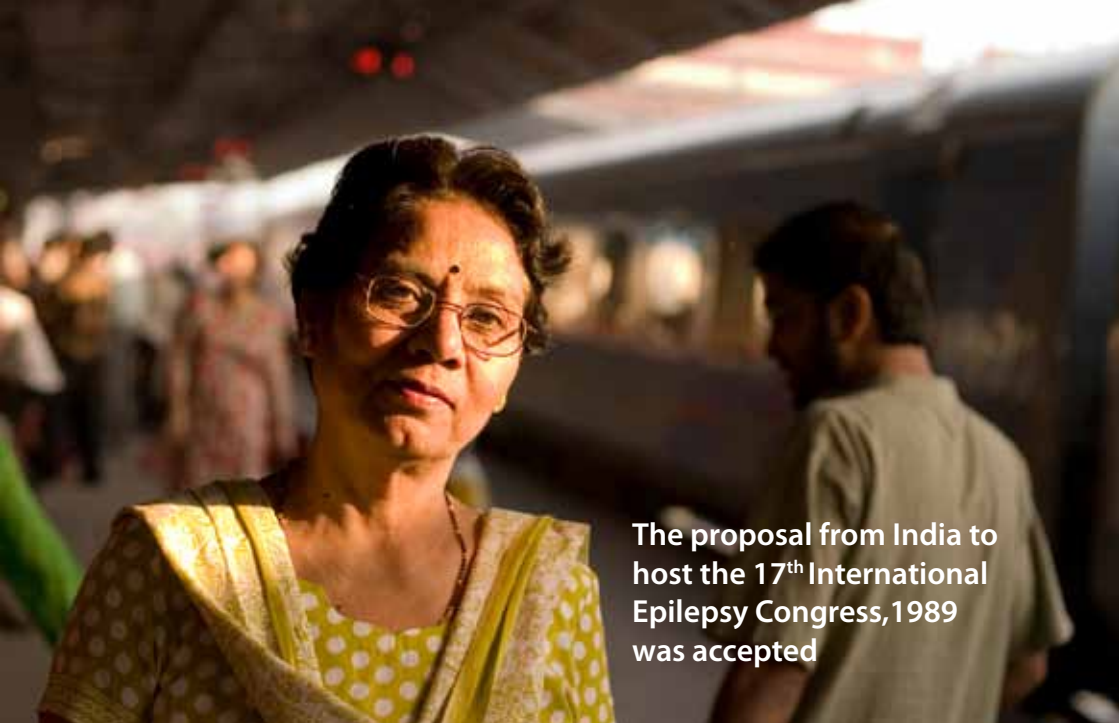
Presentation of Ambassador for Epilepsy Awards 1985

A target of this meeting was to determine IBE's role in the coming years. After the dissolution of EI both international epilepsy organisations had to identify their own fields of focus again; to set rules in order to avoid overlap in the work of each body; and to secure good co-ordination. There was general agreement that both organisations were complementing each other. Each had its own activities and there were joint ventures such as

the biennial international congresses. During the meeting, IBE proposed that the Commissions on Drivers Licences and on Developing Countries become joint IBE/ILAE activities.

An important item on the IBE agenda was discussion on a draft long-range plan. As IBE's funds were extremely limited, all activities would have to be funded by external sources. As this meant that activities had to be prioritised, it was decided to focus on a Workshop on Employment in 1986 and on a Seminar on Public Education in 1987. In addition, funds permitting, an audiovisual festival would be held every four years, the first one to take place in India in 1989²⁹.

Both Executive Committees discussed activities of mutual interest during their joint meeting, A procedure for organising future joint meetings was



The proposal from India to host the 17th International Epilepsy Congress, 1989 was accepted

approved. The invitation from India to hold the 1989 congress in that country was accepted and it was agreed that satellites might be organised, provided they did not conflict with any part of the official Congress programme, including business meetings and social events.

A further point for discussion was the possibility of establishing closer collaboration between IBE/ILAE and the WHO. This discussion took place in the presence of a WHO representative, Dr John Orley, senior Medical Officer.

On 1st June 1986 IBE appointed Bob Waiszfisz, a Dutch national, as its new Executive Director. The IBE office moved to the Hague, where Mr Waiszfisz was based.

During the 1987 spring meeting the Executive Director tendered his resignation as it had become apparent that the part time basis on which he and IBE worked together was insufficient for planning future activities.

As a result, the IBE office moved to Heemstede.

During the Joint Meeting of the IBE and ILAE Executives in September of that same year, Congress Guidelines were reviewed and approved. Included in these guidelines was the decision that a contract be signed between the local congress organisers and IBE/ILAE concerning finances, structure and format of the congress, etc. The proposal submitted by Brazil to hold the 1991 congress in Rio de Janeiro was accepted, with Australia as first reserve.

Issues discussed during the 1987 IBE Executive spring meeting concerned:

- Conditions under which organisations and institutions, in countries which had already a national representative body as a chapter of IBE, could be admitted as a non-voting member, under the name '*Friend of IBE*'
- Appointment of a Nominating Committee to prepare the upcoming election slate. This Committee was chaired by the Past President and consisted of people who themselves were not in a position to be nominated (J Autry, USA; A Arcaya, Chile; F Castellano, USA (Chair); and J Loeber as an ex-officio member.
- The first IBE sponsored European Conference on Epilepsy & Society.

During its spring meeting in 1988 (Basel, Switzerland), amongst the issues discussed by the Executive Committee was procedures for disaffiliation of non-paying chapters.



Bill McLin, USA, IBE President
1989-1993

The following topics were discussed during the 1989 spring meeting:

- Expansion of IBE
- The IBE Travellers Handbook.
- The 2nd Epilepsy & Society Congress to be held in Dublin, Ireland in 1990
- The '*Principles of Good Practice for Employers*' developed by the Employment Commission and adopted by both IBE and ILAE.
- The 18th International Epilepsy Congress in Rio de Janeiro, Brazil, organised jointly with ILAE, during which the 2nd Audiovisual Festival would be organised.

A slate of new officers for the IBE Executive Committee, prepared by the Nominating Committee, was adopted by the General Assembly.

In 1990 the Executive Committee approved the request of ILAE to use the IE News to communicate with its chapters.

The setting up of a European commission within the structure of IBE was discussed, in order to meet the requirement of the European Commission in Brussels that global organisations form a European structure in order to be eligible for European Commission funding. This commission would be the first IBE Regional Committee.

A document was prepared to be submitted as a statement to WHO on 'Basic legislative issues supporting people with epilepsy'. It was emphasised that "wherever legal restrictions for people with epilepsy exist, they should be amended as soon as possible".

From a financial point of view IBE was faring well. This allowed for some funds to be spent on an IBE annual report and to increase the annual budget allowance for IBE's five commissions.

The setting up of a **Commission on Epilepsy and Insurance**, whose aim would be to examine ways of resolving the problems and difficulties faced by people with epilepsy when looking for insurance, was approved by the Executive Committee when it met at the time of the International Epilepsy Congress in Rio de Janeiro.

The minutes of the IBE Spring meeting (1993) report on a discussion concerning dual chapter membership where one chapter is a member of both IBE and ILAE. After a long discussion there was consensus that if the structure of an applicant association met the IBE membership criteria, irrespective of the criteria of ILAE, the application should be accepted.

During their meeting in London, UK, November 1994 and again in 1995, the Joint Executive Committee discussed the relationship between IBE/ILAE and the pharmaceutical industry. A document, entitled: '*Guidelines for Industry Support of IILAE/IBE sponsored Educational and Scientific Activities*', was agreed on in 1995.

These guidelines were intended to apply to all ILAE or IBE sponsored activities, including meetings and workshops organised by commissions. The objective was to create a framework whereby partnership with the pharmaceutical industry would achieve mutually beneficial goals.

The spring meeting in 1995 was largely devoted to discussion concerning IBE's finances, and a Finance Committee was appointed.



Horse drawn carriages were used to ferry delegates between session halls at the 22nd International Epilepsy Congress, Dublin 1997

Organisation of the **22nd International Epilepsy Congress**, planned to be held in Venice and subsequently moved to Florence, Italy, 1997, remained problematic. Finally, the Executive Committees had no other option but to decide to move to an alternative venue for the 1997 congress. The original bids for 1997 were reconsidered. Both Ireland and Finland were approached informally and Ireland accepted the invitation to hold the 1997 congress.



Seoul, Korea, hosted the 1st Asian & Oceanian Epilepsy Congress 1996

The **Inaugural Asian & Oceanian Congress** took place in 1996 in Seoul, Korea and marked the beginning of the development of another regional committee, following the European example. The congress had been very successful and attracted approximately 1,000 participants.

The compatibility of the ILAE and IBE Constitutions concerning the roles of

their respective chapters was also a point for discussion. Both IBE/ILAE Secretaries proposed to draft new bylaws to address the following issues:

- i. that each IBE chapter should cooperate with its ILAE equivalent to ensure maximum efficiency in their activities
- ii. that each IBE chapter should be pro-active in promoting the establishment of an ILAE chapter in their country where one did not exist.

A Commission on Behavioural Control was set up. A proposal was put forward to the Executive Committees of IBE and ILAE to create the post of Professional Congress Organiser.

IBE was invited to join ILAE and WHO in conducting a global campaign to raise the awareness of people and their governments about epilepsy.

During the 1998 Joint Executive Committee meeting the feasibility of proceeding with the organisation of the **24th International Epilepsy Congress**, due to be held in Indonesia was discussed, given the unrest and instability in that country. It was proposed to invite Argentina, which had been chosen as the second choice during the bidding procedure. Indonesia would be invited to bid for the 2003 congress with guaranteed short listing.

It was also decided to set up a sub-group to develop procedures for the

Social Accomplishment, Lifetime Achievement and Ambassador for Epilepsy awards. The creation of an International **Epilepsy Resource Centre** was discussed on a number of occasions and, finally, such a centre was established in Switzerland, at the Swiss Epilepsy Centre in Zurich

In 1999 the Executive Committee discussed the fact that IBE had been constituted in the United States of America. There seemed to be no other reason for this other than historical. It was decided to research the most appropriate country for registration based on financial, legal, tax issues and accessibility, using the USA as a benchmark. Finally in 2002, following review, it was recommended that IBE make no change regarding its place of registration

In 2001, the **IBE website** was launched during the 24th International Epilepsy Congress in Buenos Aires, which provided IBE with its most interactive communications channel.

In an article written by Philip Lee on IBE's **Long Term Strategy**, the IE News

reported in 2003: *"Epilepsy and those affected by the condition are experiencing a process of dynamic change reflected by changes in worldwide economic, technological, medical, political and social circumstances. The current and forecast future demand on IBE's resources outweighs the organisation's ability to satisfy the demands and expectations being placed upon it. ..."* Thus IBE needed to equip itself for the future, review its constitution and its long term strategy³¹.



Delegates received a mousemat to celebrate the launch of IBE's website



Promising Strategies Program: providing funding to IBE members to support initiatives aimed at improving life skills and life quality for people with epilepsy



In 2005 the **Promising Strategies Program**, which had been proposed by the Secretary General, Eric Hargis at an IBE Management Committee held in Washington DC in December 2004, was launched, following the preparation of a draft proposal which was presented to the International Executive Committee for its review. The Promising Strategies initiative would fit within IBE's commitment to find new and innovative solutions to problems affecting people with epilepsy and those who care for them globally. It was proposed that the initiative would provide a limited amount of funding to IBE members, on a competitive basis, for projects. The original idea for the Promising Strategies Program had come from a successful capacity building workshop, organized by Epilepsy Foundation in 2004. While all participants to the workshop had 'built' initiatives during the course of this event, few were able to put these into practice within their own organizations due to lack of funding.

Also in 2005 the **IBE Solidarity Fund** was introduced, following the change in the dues payment structure in the new Constitution that came into effect in January 2005. The new structure saw many members paying dramatically lower fees than in previous years. The idea of the fund was to encourage members to donate some of the difference between the old and new dues payment to the Solidarity Fund. The purpose of the fund was to support members in less well off countries. Since its creation, the Solidarity Fund has helped augment the level of funding available for Promising Strategies initiatives.

During the Joint Executive Committee meeting in 2005 the decision-making process was discussed. It was recognised that the Joint Executive Committee

(JEC) did not have a legal status, thus it had been necessary for both IBE and ILAE to separately agree on common issues prior to their discussion at JEC meetings. This issue was now dealt with in the bye-laws adopted by both IBE and ILAE, stating that any decisions made by the JEC had to achieve a majority vote of both IBE and ILAE members as well as an overall majority within the JEC. Thus separate voting would no longer be necessary.

In order to avoid any trace of conflict of interest, the Executive Committee, from its 2006 spring meeting onwards, began each meeting with a declaration of conflict of interest to allow anyone attending to declare if they had a conflict of interest with any items on the agenda. Any conflict of interest indicated would be listed in the minutes of the meeting and the person or persons involved could leave the room while the agenda item was being discussed.

During this meeting it was also agreed to review the website in order to highlight areas that needed to be changed and introduce new pages and services on the site.

Congresses formed an important element of the joint activities of IBE and ILAE and took up a considerable a considerable amount of the time allocated to the Joint Executive Meetings. Regional Conferences became more important as they expanded, both in numbers and in quality, which becomes clear, when reading the minutes of the Joint Executive Committee Meetings from this period.

In 2007 IBE applied for **Consultative Status on the Economic and Social Council (ECOSOC) of the United Nations**, which was recommended and reviewed and IBE was approved in July of the same year as an NGO with Special Consultative Status on ECOSOC. As such IBE would be invited to attend council meetings and would have the opportunity to present reports. The position would allow IBE to influence issues related to epilepsy.



In order to encourage expansion of the Bureau, the idea of setting up a special Membership Drive 2008 was discussed, to help fill the gaps where IBE was still not represented on the world map. The rationale was to acknowledge the support of Members who assisted IBE in identifying new Members. The goal of the Membership Drive was to have 10 new members by the end of 2008. Another issue discussed was the small geographical mass of some countries where there was no IBE member and the need to consider how best to address this situation so that membership can be facilitated. A third IBE membership category – that of Regional Member – where two or more smaller countries could apply jointly for membership was considered. In 2008 a change was made to the IBE Constitution to accommodate this new membership category.



At the Communiqué Awards Ceremony, July 2008, from left: Marion Clignet (Olympic medalist living with epilepsy), Susanne Lund (IBE President 2005-2009) and Ursula Davis (UCB Pharma)

Also in 2008, IBE was awarded two very important Communiqué Awards for the **Action Zone!** board game that had been developed by IBE and UCB Pharma. IBE was presented with the awards for Best International Public Relations Campaign and Communiqué Campaign of the Year

2008. More than 46,000 units of the game were circulated to IBE member associations worldwide with the support of UCB Pharma.

Employment workshop, York (UK): During this workshop in 1986 the Employment Commission began preparations for a Employment Seminar to be held in Jerusalem, Israel.

Chapter Survey (1987): to obtain an up to date picture of how members worked, to ensure IBE provided the best possible service to its members.

Self-help Workshop, Heeze, the Netherlands, May 1987: under the auspices of the Self-help Commission with the aim of strengthening the self-help movement and developing policy guidelines, which could be useful for starting new groups.

Seminar on Epilepsy and Employment, Jerusalem 1987: organised by the IBE Employment Commission during the 17th International Epilepsy Congress, Jerusalem 1987. The seminar covered: Neuropsychological assessment in epilepsy, Research Review, Improving conditions for the employment of people with epilepsy, etc. The proceedings were published by IBE.

Workshop on Employment: during 18th International Epilepsy Congress, New Delhi, 1989, with the purpose of informing participants about the latest developments in this field and with interactive discussion between participants and experts on how to improve the employability of people with epilepsy.

3rd Audiovisual Festival: during the 18th International Epilepsy Congress, New Delhi, 1989. The winners received a gold award - an oil lamp symbolising the light of education shining in the darkness of ignorance and the warmth of compassion and understanding for those in need.

Seminar for youngsters with epilepsy: held in Oisterwijk, Netherlands, September 1991, organised by IBE's Travel Commission. One of the activities of this seminar was a plan to organise a trip to the 3rd Epilepsy & Society Conference in Glasgow, 1992 in order to promote the involvement of people with epilepsy in international congresses.

CAMUDEC 1992: IBE's Travel Commission organised a pre-conference tour package to provide people with epilepsy with a short, but rich, cultural and social introduction to Scotland, hosted by the Epilepsy Association of Scotland.

Youth Satellite, Glasgow 1992: organised by a special Youth Committee, aimed at young people with epilepsy from different countries who came together to share their experiences and to learn from each other by means of cross-cultural comparisons.

4th Audiovisual Festival: held during the 20th International Epilepsy Congress Oslo 1993: consisting of workshops, sessions on specific topics, presentations to award winning productions, and continuous screening of the submitted material.



Lighting the IBE candle in Glasgow

Workshop on Public Education: held prior to the Oslo Congress in 1993, aimed at people from different countries whose day-to-day work included educating the general public. The theme was: Educate the Educators³².

Improving Quality of Life: European conference for people with epilepsy, Manchester, England, 1993. This conference was organised by the British Epilepsy Association and IBE with the objectives to: Bring together people from different countries; Provide the opportunity to address key issues of mutual concern; identify problems and propose practical solutions; learn from each other's experiences; provide the possibility to exchange information and learn more about epilepsy

Poster Awareness Campaign (PACE): which was launched in April 1993 and titled: "Independence". People with epilepsy from Europe were invited to submit images to be used in poster format to show the general public that having epilepsy does not mean that you are "different". The idea for this Campaign came from the Manchester meeting.



Workshop in Driving Licences, Brussels, May 1995: initiated by the IBE Commission on Driving Licences. The aim was to reach a consensus on acceptable risks in order to help member states achieve greater uniformity of regulations³³.

Quarantine Station Seminar 1995: organised prior to the 21st International Epilepsy Congress, Sydney, by the Selfhelp Commission, the Commission on Public Education, and the Employment Commission.

2nd Workshop on Driving Licences: held in Brussels, March 1996 with the aim of harmonising the rules governing epilepsy and driving. Recommendations from this workshop were developed and representatives of the European Union (EU) gave their assurance that these recommendations would receive careful consideration.



For a number of years, from 2000, educational courses for young people were organised by the IBE Employment Commission under the banner of the EYiE Project - **Epilepsy Youth in Europe**

5th Audiovisual Festival: held during the International Epilepsy Congress in Dublin, Ireland in 1997. The festival in Dublin focussed on commercial drama productions.

Managing Epilepsy, Dublin 1997: A workshop for people with epilepsy and their families.

Adding Employment Services: held during the 7th Epilepsy & Society Conference in Athens, Greece (2000): A professional development course organised by the IBE Employment Commission with the aim to identify the employment services that could be offered by IBE chapters and friends.

Epilepsy Youth in Europe, Athens 2000: In May 2000, 20 young people and youth workers from 16 European IBE Chapters and Friends met in Athens for a 6-day training course on the use of the internet.

PAN: Workshop organised by IBE's Public Education Commission (Athens, Greece, 2000) focussing on Perceptions, Availability and Needs.

2nd EYiE Project: '*EYiE's Wide Open*' was the name of the second EYiE Project - a 6-day event held in Germany in 2001. Its aim was to widen the EYiE network and appeal to more young people in Europe. EYiE stood for Epilepsy Youth in Europe.

IBE organised a series of **Educational Workshops** at the 25th International Epilepsy Congress, Paris 2003. The workshops included:

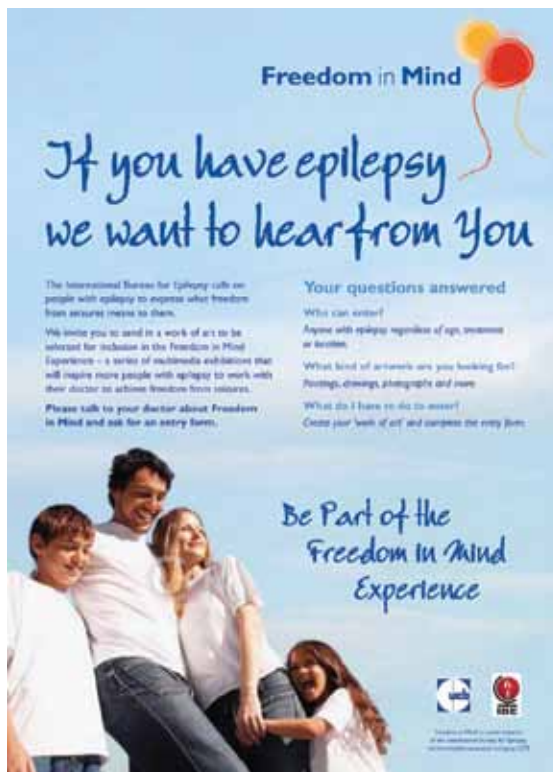
- **Masterclass Courses** for participants with some knowledge of the topics covered: Effective Public Relations, Chapter websites, Building and using Membership, Influencing Public Policy and Services Programmes.
- **Foundation Level Courses** for non-professionals working in recently established epilepsy organisations looking at: Fundraising, Membership, Service Programmes and Public Relations.

IBE Poster Campaign: A competition to develop a public awareness poster that could be understood universally, organised by the IBE Public Education Commission, with the winning entry chosen during the 25th International Epilepsy Congress Buenos Aires 2003.

3rd EYiE Project: The youth section of Caritas Malta Association, together with the IBE EYiE project obtained EU funding to host a Youth Exchange Project in Malta (2003). The project, called the 'EYiE of Horus' aimed at creating an international forum of young people exploring what it was like to be a young person with epilepsy in Europe, what it meant to European society, and how to tackle the multicultural social exclusion they often experienced.

4rd EYiE Project: Chile 2004, involving 40 young people from Europe and Latin America. As a result the Latin American -Europe Youth Declaration was drawn up and presented to the Deputy Health Minister of Chile.

EYiE8 Epilepsy: titled 'Gaining the Initiative', the event took place in Sligo, Ireland in 2005. The aim was to inform participants about the European Union Youth Programme and to build the skills needed to apply for Youth Programme funded projects.



Members Poster Display, Paris 2005: All members were invited to take part in a special Members Poster Display during the congress as a means of highlighting the work and achievements of IBE member associations.

Freedom in Mind Experience

An artistic project that invited people with epilepsy to express what freedom from seizures meant to them. People were asked to submit artwork to be selected for inclusion in the Freedom in Mind Experience – a series of multimedia exhibitions to inspire more people with epilepsy to work with their doctors to achieve freedom from seizures.

The Excellence in Epilepsy Journalism Award: was launched in 2008 by IBE and UCB to encourage journalists to raise awareness of epilepsy and to help break down the barriers surrounding epilepsy through the use of correct terminology when writing and reporting on epilepsy.

Publications: Over 30 publications were produced during this period. These ranged from the very popular Travellers Handbook (which was produced in 1986 and revised in 2009, congress proceedings, educational manuals, and a range of reports and leaflets.



Membership

During the meeting of the IBE Executive Committee in Jerusalem (1987) it was decided to try and actively expand the number of chapters. In many countries there were organisations such as epilepsy centres, schools and foundations that would have liked to be involved in international epilepsy activities and to receive first hand information about these activities.

By creating a non-voting membership category, under the name "*Friend of IBE*", requests from such organisations could be met. These entities could now join IBE and enjoy the same privileges as member organisations, other than the right to vote. Later it was decided to divide the Friends category into profit making entities, i.e. donors or supporters and those who were non-profit organisations.

In 1996 the concept of introductory provisional membership category for organisations wishing to become members was proposed by the Executive Committee. This would allow time for applicant organisation to demonstrate commitment to IBE and to make constitutional and other changes required to meet full membership criteria. This proposal was recommended to the General Assembly in 1997.

Membership Dues

To identify a fair solution regarding the issue of membership dues, the General Assembly accepted that to remain in good standing (with voting rights)

a chapter should at least have paid US\$250 per annum. However, the manner in which dues payments were calculated – US\$0.50 for each member of the chapter - remained unchanged Based on correspondence received from chapters during the IBE Executive Meeting in Israel, at the time of the Jerusalem congress later that year, it was decided to reduce the minimum dues to US\$150 per annum.

In 1993 a new dues category was created for profit organisations, named donors and supporters, with a minimum fee of US\$1,500 per annum.

In 2008, the membership dues were once more topic of discussion and a Committee reviewed the World Bank figures and proposed to introduce the following 3-tier dues structure for Full Members:which would see Full Members in countries:

1. US\$10 where country Purchasing Power Parity (PPP) was less than US\$3,000
2. US\$25 where PPP was between US\$3,001 and US\$8,000
3. US\$150 where PPP was in excess of US\$8,000 . This category would also be encouraged to donate to the Solidarity Fund.

The Committee recommended that once a Member was two years in arrears with payment, assertive action was required. When Associate Members were two years in arrears with payments they should be advised that, unless payment was received by the end of May of the year in question, they would be presented to the General Assembly for disaffiliation. If a Full Member was two years in arrears, provided there was significant communication, efforts would be made to find a resolution. The office would continue to communicate with Full Members not in good standing to try and resolve any outstanding dues payments. Where there was no communication from the association, the Member would then be considered for disaffiliation.



JOINT PROJECTS & INITIATIVES

Over the years, a number of projects have been executed in collaboration with ILAE: International and Regional Epilepsy Congresses; International Resource Centre, Zurich; and Congress Awards. Two joint projects are highlighted here in more detail.

EUCARE (European Concerted Action and Research in Epilepsy)

This project was inaugurated in May 1998 in response to the publication of a paper produced by the Commission on European Affairs (CEA) of ILAE³⁴. In its later stages EUCARE became a joint initiative of ILAE and IBE supported by an unrestricted educational



grant from UCB, whose goal was to raise the profile of epilepsy across Europe through educational and political actions. It had two main areas of activity: research and advocacy. EUCARE produced a European White Paper on Epilepsy accompanied by a "Call to Action", which was launched at the European Parliament in Brussels on 22nd March 2000.



John Bowis, MEP, at the launch of the European White Paper on Epilepsy

EUCARE aimed at developing strategies for improving understanding of epilepsy; promoting exchange of knowledge; supporting research; and encouraging the promotion of epilepsy as a public health priority among governments and health authorities. These strategies were dealt with by the FONDE ("Following Outcomes in Newly Diagnosed Epilepsy) Project and by the Political Action Group, which was set up in 2006.

In 2010 the EUCARE project was replaced by a Joint Task Force - Epilepsy Advocacy Europe (EAE).

ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadows'

Epilepsy imposes enormous physical, psychological, social and economic burdens on individuals, families and countries, especially due to misunderstanding, fear and stigma. In response to these challenges, WHO and its regional offices have joined forces with IBE and ILAE for a campaign of

concerted action to address the neglected global problem of epilepsy. The Campaign's mission statement is to improve the acceptability, diagnosis and treatment, services and prevention of epilepsy worldwide.



Members of the Global Campaign Task Force, co-chaired by Helen Cross and Shichuo Li, meeting in 2009

The Campaign's objectives are:

- to reduce the burden of epilepsy;
- to improve understanding of epilepsy;
- to promote primary and secondary prevention of epilepsy;
- to improve medical, social and psychological care for persons with epilepsy;
- to reduce the limitations faced by people with epilepsy and their families.

The ultimate objective is to ensure that governments and healthcare providers place epilepsy on the health and development agenda in order to formulate and implement cost-effective responses to epilepsy.

The Campaign was launched in 1997 in Geneva and in Dublin and in its first three years concentrated on increasing awareness, creating acceptance and improving education, including within the League, Bureau and WHO themselves. The most important achievement in that period was the acceptance of the Cabinet Paper on the Global Campaign in December 1999, which raised its status to one of the highest priorities of WHO.

The experience of the first phase of the Campaign gave the rationale for the second phase, with the new, more ambitious goal of improving health care services for treatment, prevention and social acceptance of epilepsy worldwide. The second phase was launched in Geneva in February 2001 in the presence of Dr Brundtland (Director General of WHO).

On a global level, the main activities of the Campaign include: assisting in regional conferences and developing Regional Declarations; preparing publications; coordinating Demonstration Projects; assessing country resources; drafting Regional Reports; and assisting the development of evidence based guidelines.

IBE's Constitution – a living document

As mentioned earlier, IBE's first Constitution, drafted in 1963, was not formally adopted until September 1966. As with every constitution changes in how IBE operates, as well as changing times, have called for revisions to the original wording of the 1966 text. Amendments were made in 1978, 1985, 1993, 1997, and again in 1999. As IBE reached the end of the 20th century, it was clear that a new constitution was required in order to revise Articles that had been in place for more than 40 years. A Constitutional Working Group was charged with drafting the new constitution, which was adopted on 31st December 2004. The major changes included in this new constitution were:

- Constitutional recognition of the IBE's seven Regional Executive Committees;
- introduction of IBE's first open elections for positions on the International Executive Committee and on the seven Regional Executive Committees;
- The introduction of one member, one vote for all ballots and the means to hold ballots electronically, rather than relying on the biennial General Assembly as had previously been the case;
- A change in membership titles from Chapter and Friend to Full Member and Associate Member;
- Changes in the dues structure.

The new constitution became active on 1st January 2005. An amendment was made in 2009. In the last few years, it has become evident that some further changes are required in the current constitution and a Governance Task Force has been created to carry out a major new review and to propose the necessary amendments. It is expected that the work of the task force will be completed before the end of 2011.

So, as we come to the end of the first 50 years of busy existence IBE has, in a sense, come full circle, with a new constitution to be drafted. Looking back at what has gone before, at the achievements celebrated, at the difficulties overcome, IBE can, with confidence, gaze forward in anticipation to what lies ahead in its drive to improve the lives of all people living with epilepsy!



IBE: shining a light on epilepsy for 50 years

Past & President Executive Committees

1966-1969

President: Mrs E Grass, USA

Treasurer: Ms I Gairdner, UK

Secretary General: Mr G Burden, UK

Vice Presidents:

- Dr A Arcaya, Chile
- Dr M Lund, Denmark
- Dr KA Melin, Sweden

1969-1973

President: Mrs E. Grass, USA

Treasurer: Dr AE Walker, USA

Secretary General: Mr G Burden, UK

Vice Presidents:

- Dr A Arcaya, Chile
- Dr M Lund, Denmark
- Dr KA Melin, Sweden

1973-1977

President: Mrs E Grass, USA

Treasurer: Dr AE Walker, USA

Secretary General: Mr G Burden, UK

Vice Presidents:

- Dr OM Jones, UK
- Dr M Lund, Denmark
- Dr KA Melin, Sweden

Honorary Editor IE News:

Prof H Meinardi, Netherlands

1977-1981

President: Prof H Meinardi, Netherlands

Past President: Mrs E Grass, USA

Treasurer: Mr OM Jones, UK

Secretary General: Dr RHE Grant, UK

Vice Presidents:

- Dr F Castellano, Italy
- Mrs P McCall, USA
- Dr KA Melin, Sweden

1981-1985

President: Dr F Castellano, Italy

Past President: Prof H Meinardi, Netherlands

Treasurer: Mr JN Loeber, Netherlands

Secretary General: Dr RHE Grant, UK

Vice Presidents:

- Mrs J Beaussart-Defaye, France
- Dr RL Masland, USA
- Prof R Canger, Italy

1985-1989

President: Mr JN Loeber, Netherlands

Treasurer: Mr WM McLin, USA

Secretary General: Dr RL Masland, USA

Vice Presidents:

- Mr RWP Gourley, Australia
- Prof R Canger, Italy
- Mrs J Beaussart-Defaye, France

Editor IE News: Mrs HM de Boer, Netherlands

1989-1993

President: Mr WM McLin, USA

Past President Mr JN Loeber, Netherlands

Treasurer: Mr RWP Gourley, Australia

Secretary General: Mrs HM de Boer, Netherlands

Vice Presidents:

- Dr MP Canevini, Italy
- Mrs L Hyvärinen, Finland
- Dr KS Mani, India

Editor IE News: Dr RL Masland, USA

1993-1997

President: Mrs HM de Boer, Netherlands
Past President: Mr WM McLin, USA
Treasurer: Mr R Holmes, Ireland
Secretary General: Dr MD Hills, New Zealand

Vice Presidents:

- Mrs J Cochrane, Scotland
 - Mr J Falk-Pedersen, Norway
 - Dr R Matsutomo, Japan
- Editor IE News: Dr J Oxley, UK
Honorary Executive Director: Mr JN Loeber

1997-2001

President: Mr R Holmes (to August 1999)
and Mr P Lee (from August 1999)
Past President: Mrs HM de Boer, Netherlands
Treasurer: Mr J Falk-Pedersen, Norway
Secretary General: Dr MD Hills, New Zealand

Vice Presidents:

- Mrs J Cochrane, Scotland
 - Mrs P Maehara, USA (to June 1998)
 - Dr CC Park, South Korea
 - Prof E Cavalheiro, Brazil (from May 1999)
- Editor IE News: Dr R Kale, India

2001-2005

President: Mr P Lee, UK
Secretary General: Prof E Cavalheiro, Brazil
Treasurer: Mr J Falk-Pedersen, Norway

Vice Presidents:

- Mr E Hargis, USA
- Dr MD Hills, New Zealand
- Dr M Mo-Song His, Taiwan
- Dr A Covanis, Greece

ILAE representatives:

- Prof G Avanzini, President
- Dr N Fejerman, Secretary General
- Prof J Sander, Treasurer

Editor IE News: Mrs S Lund, Sweden

2005-2009

President: Mrs S Lund, Sweden
Past President: Mr P Lee, UK
Secretary General: Mr E Hargis, USA
Treasurer: Mr M Glynn, Ireland

Regional Vice Presidents:

- Dr Z Gedlie Damtie, Africa
- Dr A Alsemari, East Mediterranean
- Dr A Covanis, Europe
- Dr C Acevedo, Latin America
- Mrs M Secco, North America
- Mrs A Hung, South East Asia
- Dr SL, Western Pacific

ILAE representatives:

- Prof P Wolf, President
- Dr S Moshé, Secretary General
- Prof M Brodie, Treasurer

2009-2013

President: Mr M Glynn, Ireland
Secretary General: Mr Eric Hargis, USA (to
September 2010) and Dr C Acevedo, Chile
(from January 2011)
Treasurer: Mrs G Tan, Singapore
Past President: Mrs S Lund, Sweden

Regional Vice Presidents:

- Mr A Zimba, Africa
- Dr A Alsemari, East Med
- Dr J Mifsud, Europe
- Dr C Acevedo, Latin America
- Mrs M Secco, North America
- Dr V Saxena, South East Asia
- Dr SL Lai, Western Pacific

ILAE representatives:

- Dr S Moshé, President
- Dr S Wiebe, Secretary General
- Prof E Perucca, Treasurer

References

1. International League Against Epilepsy 1909-2009: A centenary history. Eds. Simon Shorvon et al. Wiley-Blackwell 2009
2. Harry Meinardi: In the beginning. International Epilepsy News, Issue 142-2001, p. 19-21
3. George Burden: Social Aspects of Epilepsy. *Epilepsia* 4th S. Vol. 3 1962, p. 201-204
4. Francis L McNaughton. The President's Report, *Epilepsia* 7 (1966) p.80-82
5. George Burden. Vienna. Newsletter no. 6, May 1965
6. George Burden, Meeting of the Bureau, Newsletter no. 7 , 1965
7. George Burden, Symposium on Driving Licences. Newsletter no. 7, 1965
8. George Burden, Visit of the Secretary General of the Bureau to the President of the International League Against Epilepsy. Newsletter no. 10, Autumn 1966
9. Harry Meinardi: Look back with pride. International Epilepsy News, Issue 2-2010; p. 4-5
10. George Burden Subscriptions. Newsletter no. 12, July 1967
11. George Burden: Council Meeting in Amsterdam. Newsletter 27, October 1971
12. Mogens Lund: From Dr Mogens Lund. Newsletter no. 28, January 1972
13. George Burden: So Far so..... International Bureau for Epilepsy newsletter no 34, September 1973
14. David O Daly, J Kiffin Penry, Ellen R Grass, George S Burden: Epilepsy International Newsletter no. 39. December 1974
15. Francesco Castellano: El speaks. Epilepsy International News, no. 66, p. 2-3, December 1981
16. Mogens Dam, To merge or not to merge.....Epilepsy International News no. 66, p. 3, December 1981
17. Francesco Castellano, El speaks. Epilepsy International News, no. 68, p. 2-3, July 1982
18. Francesco Castellano, Mogens Dam. El speaks. Epilepsy International News, no. 78, p.2, January 1985
19. Francesco Castellano: El speaks. Epilepsy International News, no. 79, p. 2, March 1985
20. International Bureau for Epilepsy Newsletter, no. 37, June 1974. p.8
21. Harry Meinardi, Collective Responsibility. Epilepsy International Newsletter, no. 48, p. 1-2, March 1977
22. Driving Licences. Epilepsy International News, no. 64, p. 1-3/9, 1981
23. International Glossary of Anticonvulsants. International Newsletter, no. 16, November 1968

24. Report of the Secretary General to Council Meeting. International Epilepsy Newsletter, no. 22, July 1970
25. International Glossary of Anticonvulsants. International Newsletter, no. 34, p. 2-3, September 1973
26. B Kulig, WOPSASSEPY I: The first workshop on the psychosocial assessment of persons with epilepsy. Epilepsy International News, no. 60, p. 7, March 1980
27. Harry Meinardi, El. speaks. Epilepsy International News, no. 60, p. 2-3, March 1980
28. Epilepsy International. Epilepsy International Newsletter, no. 52, March 1978. p. 3
29. Joop N Loeber, I.E speaks, International Epilepsy News, no. 84. p. 2, July 1986
30. Joop N Loeber, IBE speaks. International Epilepsy News, no. 92, p. 2-3, 1988
31. IBE sets its future course, International Epilepsy News, Issue 4 - 2003 p. 12-13
32. Catherine Dowds, IBE holds a seminar on public education. International Epilepsy News, no. 113, September, p. 8-9, 1993
33. Deirdre Carroll. Workshop agrees on driving licence regulations for people with epilepsy. IE News, no. 122, p.17-18. December 1995
34. Brodie MJ, Shorvon SD, Canger R, Halasz P, Johannessen S, Thompson P, Wieser HG, Wolf P. Commission on European Affairs: appropriate standards of epilepsy care across Europe. Epilepsia 1997; 38: 1245-1250

About the Author



Hanneke M de Boer has worked in the field of epilepsy since 1966. She first presented internationally at the International Epilepsy Congress held in Amsterdam. She chaired the first IBE Employment Commission in 1983 and was appointed editor of the International Epilepsy News in 1985.

She was IBE Secretary General 1989-1993 and President 1997-2001. In these roles she was also an ex-officio member of the ILAE Executive Committee. She has been a member or chair

of a number of IBE Commissions.

In 1999 she joined the ILAE/IBE/WHO Global Campaign Against Epilepsy secretariat and was co-chair from 2001 to 2005. She is still involved in the campaign to this day.

Mrs de Boer works at a large epilepsy centre (Stichting Epilepsie Instellingen Nederland) originally as a vocational consultant and later charged with training of other vocational consultants. During the last 10 years she has been involved in developing international contacts for this centre, which was designated a WHO Collaborating Centre for Research, Training and Treatment in Epilepsy in 2004.

Nationally and internationally, she has presented and published numerous papers on the social aspects of epilepsy, in particular employment and employability of people with epilepsy; the influence of stigma on the lives of the people; and the burden of epilepsy.

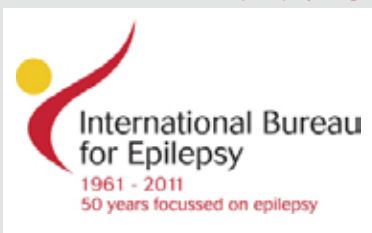
Mrs de Boer has received a number of awards, including the Award of the Dutch Christian Society for the Care of people with Epilepsy, the IBE/ILAE Ambassador for Epilepsy Award, the Spike and Wave Award of the Dutch Branch of ILAE, the IBE/ILAE Award for Social Accomplishment, the IBE/ILAE Lifetime Achievement Award; and the Dutch Royal decoration: Officer in the Order of Oranje Nassau.



IBE has a vision of the world where everywhere fear and ignorance about epilepsy are replaced by understanding and care.



International Bureau for Epilepsy
 Email: ibedublin@eircom.net
 Website: www.ibe-epilepsy.org



The International Bureau for Epilepsy was founded in Rome in 1961. This condensed history of the first 50 years of IBE is published to celebrate its Golden Jubilee anniversary.

Documented are the first tentative steps of the Bureau, its trials and triumphs over the course of half a century, and its determined efforts to improve the social condition and quality of life of all people with epilepsy and those who care for them.

Compiled by Hanneke M de Boer

Edited by: Ann Little
 Layout and Design: Susanne Lund