

## **The Historical Archive of ILAE Papers and Documents Now available at the Wellcome Trust in London**

The ILAE has a checkered history. It was founded in 1909 at a meeting in Budapest and over the next 5 years grew and expanded into an energetic and active organization, with members in 19 countries. The Great War ended all this and from 1914 to 1934, the organization ceased completely to function. In 1934, at a meeting in Lingfield in England, ILAE was resuscitated and over the next 5 years, 5 chapters were formed. The Second World War again abruptly interrupted all activity, although a skeleton organization continued to exist in the United States. In 1946, international activity again resumed and since then the ILAE has expanded and grown. By 1981 there were 29 chapters and now there are over 100. Over these years, ILAE has also grown in importance, and the organization has had a significant influence on the development of epilepsy in the twentieth century.

This history is important to preserve, for its own sake, for the sake of the history of epilepsy, and also because all organisations are enriched by their history. History is institutional memory, and a knowledge of history informs future decisions, and helps avoid repeating mistakes of the past.

So what has happened to the documents and papers in which ILAE history is preserved? Sadly, much of the early material has disappeared. This is largely because documents and papers were kept by individuals on an ad-hoc and informal basis, and over time these were simply lost. Natural calamity, the dislocation of war and the changing fortune of individuals all took their toll. Internal disagreements and conflicts within the ILAE also played a role. In 1957, the then Secretary-General B Ch Ledebøer, whose personal life was turbulent to say the least, fell out with his successor and he destroyed the papers he had accumulated. In 1974, Otto Magnus, the then Secretary General, became embittered from his arguments with Margaret Lennox-Buchthal and the US members of the Executive, and recorded in the Executive Committee minutes that he did not wish to transfer any of his own accumulated documents. Similarly, Henri Gastaut in 1973 retained all his papers. Luckily for the ILAE, many of the documents and records of the early years were reproduced in the pages of *Epilepsia*, and this provides a rich and permanent source of early information. However, with the initiation of the 4<sup>th</sup> series of the Journal in 1959, the journal began to focus on scientific papers and the publication of internal ILAE papers largely ceased.

Fortunately, from the 1950s onward, some documents and papers have survived, and from the 1970s the record is relatively complete. These papers form an archive which in those years continued to be passed from the office of one President or Secretary to the next, a precarious arrangement as previous experience had demonstrated. It was only in the 1980s that an effort was made, by Harry Meinardi, to catalogue and centralise the papers. In the early 1990s, the documents were transferred to the Epilepsy Centre in Heemstede, and then in 1999, the semi-organized archive was moved in part to the Epilepsy Centre in Bethel and in part to the ILAE offices in Brussels. Other papers remained in the

offices of previous ILAE members and officers. Water damage occurred to some of the papers in Bethel, and by the turn of the century, the archive was in a rather dilapidated and sorry state.

In 2005, a concerted effort was made to secure the future of the archive. After protracted debate, all the papers in Bethel and Brussels were moved to the Swiss Epilepsy Centre in Zurich, where they were stored in dry and appropriate surroundings. In 2006, Giselle Weiss indexed, arranged and boxed the archive in a modern fashion, and for the first time, an index of the archive contents was placed online. Nevertheless, the inaccessibility of the archive remained a recurring problem, and in 2013, the ILAE approached the Wellcome Trust in London with a view to moving the papers into the Trust's Archive and Library section. The Wellcome Trust is one of the world's premiere medical history centres. It is a long-established and very well funded non-profit organisation. The mission of its Archive and Library section is to provide freely available resources to scholars, and it has already an extensive archive of important papers in the field of neuroscience. It provides a very professional and state-of-the-art archiving service. A preliminary meeting was held with the Trust in January 2013. Later that year, the archive in Zurich was viewed by the Trust curators, who, impressed by its quality and potential historical value, agreed to the move. On Oct 4<sup>th</sup> 2013, the archive was finally transferred from Zurich to the Trust Headquarters in London, which will now hopefully be its permanent home.

The benefits for the archive of this move, as perceived by ILAE, are:

- Custodianship by a highly professional archival setting with cutting edge resources for maintenance and conservation.
- Detailed cataloguing and, in the longer term, digitalization of selected papers for a free online accessibility
- Long term survival and security of the archive in a custom-built facility with reading room and professionally staffed.
- Accessibility to scholars and medical historians

After the move, ILAE employed a professional archivist, Ms Nicola Waddington, to sort, appraise, repackage and index the papers (based on the work of Giselle Weiss). These tasks have now been finished, and the archive is contained in 147 archive boxes and comprises 1192 records, an index of which can be accessed at <http://archives.wellcomelibrary.org/Dserve/dserve.exe?dsqIni=Dserve.ini&dsqApp=Archive&dsqCmd=overview.tcl&dsqDb=Catalog&dsqSearch=%28AltRefNo%3D%27sa%2File%27%29>. A printed catalogue was also produced which runs to 224 pages.

The archive consists of papers from 1953, and is organized into the following sections:

- Governance
- Executive Committee
- General Assembly
- Council
- Joint Executive of the ILAE and IBE
- Epilepsy International

- Chapters Commissions
- Relationship with the World Health Organisation  
International Symposia and Congresses Workshops
- *Epilepsia*
- Newsletters
- Ambassadors and Awards

The archive is the ILAE's institutional memory. It is a rich resource for scholars and anyone interested in the past, and by implication, the future of epilepsy, and it is to be hoped that its accessibility will lead to historical studies and investigations which will inevitably enhance the reputation of ILAE. As Walter Benjamin famously wrote: "Memory is not an instrument for surveying the past but its theater. It is the medium of past experience, just as the earth is the medium in which dead cities lie buried. He who seeks to approach his own buried past must conduct himself like a man digging." There are many buried treasures, awaiting rediscovery, within the pages of this ILAE collection.

The archive was officially opened, and an online catalogue and blog launched, in Oct 2014. Thus, the first phase of the reconstitution of the ILAE Historical archive has been completed.

ILAE is now moving to the next stage – and this is to collect documents from individuals around the world, which will help complete, enrich and enhance the archive. ILAE plans to launch a procedure for collecting and evaluating material. An archive is a living thing, and will be increasingly useful the more that is added, and it is to be hoped that interesting and unique material will arrive from the many ILAE members around the world. Both historical and contemporary material is needed, and you are likely to hear more about this process in following months.

Other plans under consideration include: the digitization of selected important papers from the archive so that these become freely available online; the organization and collection of contemporary archives, much of which is digital in nature and not paper-based – a challenge for all modern archivists; and the establishment of a comprehensive policy for informing and communicating the role and range of the archive.

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