

Kork, Germany: Diakonie Kork Epilepsiezentrum. Epilepsy Centre, Kork

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HISTORICAL BACKGROUND AND STRUCTURE

The Diakonie Kork Epilepsiezentrum is a non-governmental foundation with a Christian background. The Epilepsy Centre began in 1892 with the ‘*Heil- und Pflegeanstalt für epileptische Kinder*’ committed to help children with epilepsy followed by the ‘*Heil- und Pflegeanstalt für Epileptische*’ widening the spectrum to the care for adults with epilepsy in 1901. Thus, the beginnings of the Centre were characterised by long-stay residential care based on the protestant humanistic movement, which had its origin in Germany in the second half of the 19th century.

Hospitals and outpatient Epilepsy Clinics

The first hospital was founded in 1948. At that time, it included departments of general surgery and internal medicine. Facilities for children with epilepsy were installed for outpatients and inpatients in 1967 and 1968, respectively. Professor Ansgar Matthes, a member of the Medical Faculty of the University of Heidelberg at the time, was courageous enough to found and establish a real clinic for epileptic patients based on the long tradition of Kork. Due to his capabilities and commitment the Centre, we are proud to represent today became a reality.

The clinic grew and finally consisted of three inpatient wards so that a co-chair became necessary.

Professor Rolf Kruse, ex-colleague of Matthes in Heidelberg, immediately showed himself to be the best man for this position.

Since 1976 and 1978, respectively, the same hospital-based care has been offered to adults, with the same structure consisting of two chairs, Volker Blankenhorn and Gerhard Reinshagen. Today, the clinic for adults offers three inpatient wards and the intensive monitoring unit that is run in collaboration with the clinic for children and adolescents. [Figs 1 and 2](#) show two of the buildings of the Epilepsy Hospitals.

The clinic as a whole consists of 106 beds representing one of the largest Epilepsy Hospitals in Europe. Recently, the hospital for children and adolescents was completely renovated and partially rebuilt. The second stage of the ongoing building activities concerns a new hospital for adults that will be finished by the end of 2003.

During the last decade, economic and structural necessities have led to the rationalisation of epilepsy services and to the reduction and eventual closure of the other medical facilities mentioned before. This process ended with the closing of the Clinic for Internal Medicine in December 2000. On the other hand, we are considering the requirements that modern developments demand from a hospital committed to the professional care for patients with epilepsy. One important step was the opening of the new section for severely handicapped patients. Future projects include a common ward for young adolescents and adults and probably rehabilitation medicine



Fig. 1: The 'Schloss'. Two inpatient wards of the Clinic for adults are accommodated here before the new hospital building is completed. In the basement, the outpatient section for severely handicapped persons and the outpatient EEG labs are located.



Fig. 2: The new hospital for children and adolescents.

services focusing on the special needs of patients with epilepsy.

Wohnverbund (long-stay resident department)

The Diakonie Kork Epilepsiezentrum does not consist only of the hospital, which in fact is one of the younger members of the whole institution. As mentioned before, the Wohnverbund, the long-stay department, was the original core of the whole centre and is still one of the most important sections. It offers 337 places mainly for mentally and/or physically handicapped people (adolescents and adults), the majority of whom suffer from difficult-to-treat Epilepsy syndromes. Within the network of the Diakonie Kork Epilepsiezentrum, it is essential to offer outpatient and inpatient hospital care for those people living in Kork. One of the crucial objectives of modern care is to promote the independence and self-esteem of the inhabitants, to encourage their integration within the community. It is an aim of this programme to give the opportunity for people to live in apartments or families outside Kork, and to obtain work locally. This will probably result in an ongoing reduction in the Kork long-stay department.

Remaining sections

The Diakonie Kork Epilepsiezentrum consists of three further mostly independent sections. These are the Kork schools, the sheltered workshops and the community of the *Korker Schwesternschaft* (Christian Kork-based order of Deaconesses).

Schools and sheltered workshops both guarantee the infrastructure necessary for the long-stay residents. However, they offer education for work for other applicants from the local region also. In addition, the schools include the *Evangelische Fachschule für Sozialpädagogik*, where young people are educated to develop the professional skills of nursing and care of handicapped people. The whole institution benefits from this school since over the years numerous employees of the Diakonie Kork Epilepsiezentrum have been recruited to work in Kork.

Organisation and structure of the Centre

The five independent sections (Geschäftsbereiche) meet in the *Leitungskonferenz*, i.e. the conference of the section heads. This conference is hierarchically placed immediately below the *Vorstand* (leading board) which consists of two members. This board is controlled by the Verwaltungsrat, a conference of in-

dependent honorary persons elected by the members of the registered society Diakonie Kork Epilepsiezentrum that acts as the representative of the institution.

POPULATION SERVED

The Diakonie Kork Epilepsiezentrum is incorporated in the regional Health Service system. Inpatient care is financed by health insurance based on annual negotiations that fix the inpatient hospital day costs. Outpatients are treated on an individual basis by five doctors of both clinics who possess the personal authorisation to do so from the local medical federation. This guarantees that only the most experienced members of the faculty treat the outpatients. This is particularly important in avoiding the major disadvantage in the treatment of chronically ill patients, namely the frequent change of the responsible physician. People who are treated in Kork come from all over Germany. The majority live in the Southern part of the country. Thus, Kork fulfils a supraregional function. Only a small minority of referrals are from abroad.

Most inpatients are internal referrals either from the long-stay department or from the outpatient departments. However, a considerable number of the hospital referrals are from neurologists and hospital departments of general neurology from all over the country, including frequent referrals from Eastern Germany. Referrals from General Practitioners occur very rarely.

The reasons for referrals are usually difficult-to-treat epilepsies, either in order to find alternative drug treatments or to investigate Epilepsy surgery options. In addition, differential diagnosis of seizures and epilepsy is a frequent and challenging reason for referrals. Finally, psychosocial, psychological or psychiatric problems that cannot be solved in the setting of a non-specialised hospital account for a considerable percentage of patients referred to us. Most of the patients have suffered from intractable Epilepsy syndromes for years; referrals of patients with new-onset seizures are exceptional.

THE MAIN SECTORS OF THE EPILEPSY CENTRE

The Epilepsy Centre consists of five complementary sectors.

Epilepsy Centre (outpatient facilities and hospitals)

- Hospital for children and adolescents (42 beds).
- Hospital for adults (60 beds).

- Intensive monitoring unit (four beds, run together by both hospitals).
- Outpatients departments consisting of five relatively independent sections (two for children and adolescents, three for adults) covering approximately 6000 visits per year.
- Total 257 employees.

Residential care for children, adolescents and adults

- Total 337 beds are available for long-term residential care, mainly for mentally and/or physically handicapped people most of them suffering from difficult-to-treat Epilepsy syndromes.
- Total 314 employees.

Kork schools

- Oberlin School for children and adolescents offered to inpatients of the clinics, long-term residents and external pupils.
- School for specialised nursing for mentally and physically handicapped people.
- Total 79 employees.

Sheltered workshops

- With working opportunities for 320 people, 20 of them with psychiatric diseases; additional 75 places for social and educational support.
- Total 122 employees.

Korker Schwesternschaft

- Total 10 members.

PERSONNEL AND ORGANISATION

The organisation of the Epilepsy Centre (the hospitals and outpatient sections) is based on a hierarchic structure led by one director who is responsible for the economical and medical performance. Currently, this director is the head of the medical staff although this need not necessarily be the case. Both clinics have independent medical directors who are responsible for the medical care in their departments. The medical director of the whole Centre does not have the authority

to interfere. However, it is likely that the structure will be changed soon, since it has become obvious that the director of the Epilepsy Clinics (which in the special and unique Kork system is only one of five subdivisions) should have more of an economic or financial background and education. We are contemplating an arrangement whereby the medical director will concentrate on medical problems exclusively. The total staff consists of 257 employees.

The medical staff of both clinics consists of experts in the field of epileptology representing a variety of disciplines covering almost all aspects of clinical epileptology. The team consists of seven neuropsychologists, specialised and experienced nurses, technicians, social workers, and a variety of therapists.

In the long-stay department, medical care concerning epileptology is offered for adult patients by two neurologists who belong to the clinical adults department whereas children and adolescents are generally treated by an experienced paediatrician who also covers the epileptological problems of the residents. If the adult residents suffer from non-neurological problems they are treated by General Practitioners working in private practice nearby. One non-medical director leads the long-stay department.

COOPERATION AND NETWORKING

Since 1997, co-operation has existed with the University of Freiburg, Department of Neurosurgery, to maintain the epilepsy surgery programme, started in Kork more than a decade ago. This collaboration makes Kork-Freiburg one of the few fourth grade Epilepsy Centres in Germany. To facilitate services for children, further collaboration exists between both clinics and the Olga Hospital at Stuttgart and the University Department of Neuropaediatrics in Heidelberg.

It is planned to establish the status of the hospital as an academic hospital so that medical students will regularly visit the Centre to be educated in epileptology. Further scientific exchanges with the University of Göttingen are also planned. We hope that contact with our neighbours in the University Hospital of Strasbourg, which hosts one of the most active Epilepsy groups in France, will be intensified over the next few years. The first steps towards this have already been taken, successfully. Digital techniques allow co-operation with various hospitals in the area of Kork. These enable the use of diagnostic facilities within these partner hospitals, including MRI scans, SPECT and PET. We are directly involved in the diagnostic process by performing the MRI scans ourselves and are able to integrate the digital data of SPECT and PET we get from our partners. This enables us to offer all relevant diagnostic techniques without the

ultimate need to acquire all of the necessary hardware ourselves, in Kork.

EDUCATION, INFORMATION AND PUBLIC RELATIONS

Over the last few years, the Centre has been active on every level of education dealing with epileptology. Almost weekly, social workers, nurses, government officials, technicians or doctors visit us either to enlarge their knowledge about epilepsy and epileptology with 1-day courses or for more long-term study. Grants from the German Section of the International League against Epilepsy or from the Michael Donation have allowed numerous applicants to work as guest doctors in Kork. Involvement in the EUREPA program will probably allow further applicants to be invited, especially from Eastern European countries. Every 2 months external experts are invited as guest speakers to give presentations. Once a year the department for children and adolescents organises a meeting committed to special problems of neuropaediatric epileptology. An annual conference on epilepsy surgery involving collaborating partners from the Universities of Freiburg and Heidelberg takes place in Kork or Freiburg, respectively. Several research programmes result in scientific papers and appearance at national and international conferences.

One crucial target is to increase the collaboration with self-help groups and other patient organisations not only to offer the facilities of the Diakonie Kork Epilepsiezentrum to those groups but also to benefit from the ongoing exchange of ideas with patients

and relatives. Inpatient teaching programmes such as MOSES and PEPE have been installed or are about to be used.

Several years ago EPICURA was established as a charitable foundation committed to the financial support of selected projects.

FINANCIAL PERSPECTIVES AND STRATEGIC DELIBERATIONS

Kork has had to face and accept a fundamental change in financing due to the introduction of the German diagnose-related grouping system. The Epilepsy Centre is engaged in several multicentre working groups to point out the special needs of a specialised Centre in offering the necessary medical services for patients with difficult-to-treat epilepsy. From 2001 rigorous documentation is needed to make those special requirements more apparent. This documentation has been installed and is currently in use.

The financial situation of the clinics has remained stable over the past years. The acknowledgement of the fundamental role of the Centre in the health system of South Germany has led to a wide acceptance and a liberal policy from the main financing sources. However, since the system of the whole Centre is based on 'solidarity principles', the positive financial position of the clinics has been somewhat offset by deficits in the other sections resulting in a more or less breakeven situation for the whole institution. Whether or not the clinic will be able to compensate for the probable losses resulting from the introduction of the DRG system cannot be unequivocally answered yet.