



EUROPEAN RENAL ASSOCIATION

EUROPEAN DIALYSIS AND TRANSPLANT ASSOCIATION

Registered Charity n° 1060134

ERA-EDTA HISTORY

The ERA-EDTA or European Renal Association – European Dialysis and Transplant Association, is a European Medical Association whose purpose is to promote and spread progress in the field of Nephrology, Dialysis and Renal transplantation.

ERA-EDTA was established in 1964 by a group of researches-pioneers of renal diseases, when Nephrology started to develop. The first renal transplants were performed on identical twins at the end of the '50 both in Boston and in Paris, and the first dialysis on patients with irreversible renal insufficiency took place at the beginning of the '60.

ERA-EDTA has also been very important to bind together experts who took care of renal diseases gathering them at the annual congress, whose tradition has not been interrupted.

The congress has been considered since then a datum point, not only for European countries, but also worldwide, becoming in the '90 a gathering of 7-8.000 participants including physicians, nurses and other experts.

ERA-EDTA has more than 5.700 members, most of whom are from European and Mediterranean countries; members from the rest of the world are also very active (about 20%).

Starting 1986, ERA-EDTA has its own medical journal “Nephrology, Dialysis and Transplantation” published by Oxford University Press. The Journal is published monthly and includes contributions from all ERA-EDTA members and has become one of the leading international medical journals.

ERA-EDTA has become the most important and prestigious European medical association in the Nephrology field and its congresses one of the scientific events of the year.

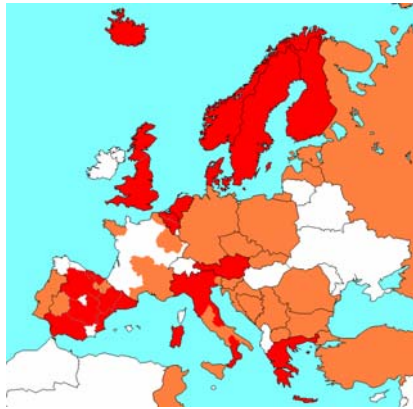
In these last years, the congress has been held in the following cities: 1999 in Madrid, 2000 in Nice, 2001 in Vienna, 2002 in Copenhagen, 2003 in Berlin, 2004 in Lisbon, 2005 in Istanbul, 2006 in Glasgow, 2007 in Barcelona and 2008 in Stockholm. In 2009 ERA-EDTA together with ISN (International Society of Nephrology) will organise the World Congress of Nephrology in Milan (Italy).



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ERA-EDTA Registry

The Registry of the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) studies the number, the treatment and the outcomes of patients who are on renal replacement therapy (dialysis or kidney transplantation) for end-stage renal disease. Its activities are outlined below.

1. Data on almost half a million patients with end-stage renal disease

Each year the 39 national and regional renal registries (shown in orange and red) in 29 European countries send their data to the ERA-EDTA Registry. Currently, the Registry holds data on

almost half a million patients treated by more than 4000 dialysis and transplant units across Europe. Based on these data the Registry produces an Annual Report which includes international comparisons on the numbers of new and existing patients and provides insight into their survival. In addition, it conducts scientific studies relating patient, treatment and country characteristics to international differences in the number and survival of these patients.

2. Education in epidemiology

In order to contribute to the quality of scientific research in the area of nephrology within Europe the ERA-EDTA organizes CME 'Introductory courses in epidemiology' twice a year. Over the past few years these courses have been attended by hundreds of nephrologists and nephrology researchers.

3. NephroQUEST - a project funded under the Public Health Programme

In September 2007 the Registry started the NephroQUEST project together with 26 partners active in the care for end-stage renal disease patients (registries, societies of nephrology, companies, quality institutes and IT-institutes). The main objectives of the project that is funded under the Public Health Programme are to select and to standardize clinical performance indicators for use by renal registries and to develop information technology for data collection. This will facilitate the EU-wide dissemination of comparable high-quality data collection so that these data will become available to stakeholders in this area of health care (clinicians, hospital management, patients and their carers, researchers and policy makers).

For more information, please contact

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Quality of care in end-stage renal disease: the importance of comparing “apples with apples”

Most patients with end-stage renal disease depend on dialysis treatment for their survival. To determine if the quality of dialysis care in one country or in one dialysis centre is different from that in another, it is essential to use comparable indicators to assess the quality of care. As such indicators were lacking at a European level, the European Renal Association - European Dialysis and Transplant Association (ERA-EDTA) initiated the *NephroQUEST* project. This project, that is being supported by the European Union under the Public Health Programme with more than half a million Euro, aims at a European wide consensus on the selection and standardization of quality of care indicators in end-stage renal disease and at further stimulating their availability. This ERA-EDTA initiative, that operates via its Registry in the Academic Medical Center in Amsterdam, was officially launched during a meeting of project partners and international nephrology researchers on November 10-11, 2007 in Amsterdam.

The wish to compare quality of care, so-called benchmarking, is not new. Already in the 1850s Florence Nightingale argued strongly that only by collecting and analyzing relevant data it was possible to determine the extent to which hospitals and other public institutions were effective in serving the patients who relied on their help.

In most European countries data on the frequency and outcome of patients with end-stage renal disease are collected by renal registries. Although registry information has contributed to the improvement of patient outcomes, there is an increasing need for information on the quality of care among clinicians, patients, health policy decision makers, insurance companies and hospital

management to assist them in their choices and decision making. By comparing day-to-day clinical practice with clinical practice guidelines and with the performance of other centres (benchmarking), the resulting information may feed into local quality improvement programmes in an effective manner.

Many registries, however, experience considerable problems in the production of clinical databases allowing such comparisons. A huge problem is posed by the process of data collection, which in some countries still makes use of paper data collection forms or other labor-intensive methods. Another problem comprises the lack of standardization of methods to determine the data to be collected.

The *NephroQUEST* project addresses both of the above mentioned problems. Together with national renal registries and a large group of European experts the ERA-EDTA Registry in the Academic Medical Center in Amsterdam has taken up the task to produce a list of standardized quality of care indicators, including a priority for data collection for renal registries. Along the same lines, action will be taken to try and solve the problem of data collection itself by reducing the working burden for medical staff to collect these data. The answer to this problem is expected to be found in the automated data extraction from electronic hospital records. Given the enormous variety of such systems across Europe *NephroQUEST* will also take a standardized approach in this matter.

The project partners are confident that a standardized ‘European’ approach with room for some subsequent adaptation at the local level will contribute to the realization of a dream in which the majority of dialysis centres in Europe will receive the information they need to improve the quality of care provided to their patients. In this way the project will assist the improvement of health systems to the benefit of all European citizens.

This press release arises from the NephroQUEST project which has received funding from the European Union, in the framework of the Public Health Programme



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Fellowship Programme

In 2006 the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) launched a **Research Fellowship Exchange programme to support mobility and scientific exchange in basic and clinical kidney research.**

This fascinating initiative has grown and expanded throughout these 2 years, giving young investigators the opportunity to increase their contribution towards the development of medicine in their countries through the results achieved with their studies in some of the best institutions in the ERA-EDTA geographical area (all European Countries and the Countries bordering Europe and the Mediterranean Sea).

The main purpose of the ERA-EDTA Fellowship Programme is to support research in the field of Nephrology in Europe, to facilitate scientific exchange and collaboration between European research institutions and -in particular- to help young investigators.

ERA-EDTA fellowships are available for both basic and clinical research in nephrology and all related areas, including the normal function of the kidney, kidney disease, hypertension, cardiovascular consequences of kidney disease, dialysis and transplantation.

ERA-EDTA offers both long-term and short-term fellowships. The long-term fellowships are awarded for prolonged visits (12 to 24 months) and are intended for advanced training through research. The Fellowship Grants cover the travel costs and a stipend for the fellow and his/her family. The stipend rates depend on the country being visited, marital status, other sources of income and number of children under 18 years of age.

The short-term fellowships are intended for visits of 1 week up to 3 months of duration and are established mainly to apply a technique not available in the home institution and to promote research collaboration between two institutions.

Every single young doctor/researcher can take advantage of this unique opportunity which will offer a new perspective on medical up-dating, work and research that can then be applied back at home once the fellowship is finished.

In only two years (2006+2007), ERA-EDTA awarded 34 young doctors with long-term and short-term fellowships!

Each year the first application deadline is April 15; while the second application deadline is October 15. For further information please visit www.era-edta.org or contact fellowships@era-edta.org.



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FROM EUROPEAN BEST PRACTICE GUIDELINES (EBPG) TO EUROPEAN RENAL BEST PRACTICE (ERBP)

A FRESH START FOR THE EUROPEAN NEPHROLOGICAL RECOMMENDATIONS

End of 2007, the Council of the European Renal Association / European Dialysis and Transplantation Association (ERA-EDTA), decided to install a commission to discuss and define the future of European nephrology guidelines. This decision was taken against the background of a changing worldwide nephrology guideline landscape, with the Kidney Disease Improving Global Outcomes (KDIGO) initiative as a body developing global nephrology guidelines having been established in 2003. The original perception that KDIGO with time would become responsible for all nephrology guidelines was to be reconsidered when the KDIGO Board of Directors from 2006 on decided to develop guidelines along selected topics and to offer global advice leaving space for local, regional, continental or country-wise fine-tuning of the guidelines developed by KDIGO as well as opportunities to develop / update guidelines on topics not covered by KDIGO.

This ERA-EDTA commission on the future of European nephrology guidelines, at that time composed of 20 members, convened a first time in January 2008, in Paris. Along with a substantial number of decisions regarding details in guideline/recommendation development, about which will be reported elsewhere, perhaps the main conclusion of the Paris meeting was to make a strict distinction between “guidelines” which should be based on absolute evidence, and expert advice which is opinion based but not or hardly evidenced, which should be reported in a way to be not perceived by the medical community as the absolute truth. Consequently, it was decided that “guidelines” should be published separately and applying a different format than “recommendations” or “position statements”. All activities developed should take into account the specific European situation and conditions.

Because these decisions were considered to emanate in a substantial change in philosophy, it was also decided to change the name of the European responsible body from European Best Practice Guidelines (EBPG) to European Renal Best Practice (ERBP).

In the nearby future several specific initiatives will emanate from this commission, which in the meanwhile at the latest ERA-EDTA Council in February 2008 in London was installed as one of the three ERA-EDTA Advisory Boards: 1) a paper announcing and explaining the change in name and philosophy described above, which has been coordinated by C Zoccali, has recently been submitted for publication; 2) a position statement regarding the latest evolutions in anemia guidelines, coordinated by F Locatelli, is currently under development and will be submitted for publication in the nearby future; 3) the writing of a position statement about the soon to be published KDIGO guidelines on hepatitis C, to be coordinated by A Covic, will be started as soon as the draft of these guidelines is available.

Later on, further initiatives will be developed, with special emphasis on updating previous EBPG guidelines such as those on kidney transplantation and peritoneal dialysis. The Advisory Board is currently being expanded to contain also members who are not nephrologists, such as nurses, patients etc.

We are convinced that these changes in scope and organization will help to increase the visibility and implementation of European nephrology guidelines and to enhance the quality of European and worldwide nephrology practice.

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EKHA European Kidney Health Alliance (EKHA)

March 8, 2007: ERA-EDTA and four partners have launched the European Kidney Health Alliance (EKHA)

On the occasion of the World Kidney Day (March 8, 2007), five major European and international organizations representing kidney health stakeholders (patients, nurses, physicians and researchers), confirm their agreement to launch the European Kidney Health Alliance (EKHA) as a joint initiative aimed at addressing kidney health issues in Europe.

The EKHA is committed to addressing the urgent need for action to raise awareness of kidney disease in Europe and in particular the benefits of early detection in preventing, or at least slowing, its progression. Members will work together to achieve a European health environment demonstrating a constant increase in quality of life and life expectancy of patients with kidney disease through state-of-the-art medical research and clinical practice, education and training and promotion of the best possible treatment of all kidney patients through exchange of best practice among and between researchers, physicians, nurses and patients.

The EKHA will work in cooperation with other health organizations at EU level to provide advice to the EU institutions and health bodies on research policies and programmes of relevance to the kidney and related medical communities, identify the topics in which EU research could deliver real and effective therapy progress and benefits to kidney patients, maintain the dialogue with EU health bodies to promote best practice in addressing the care of kidney patients, encourage the exchange of information on approaches to early detection and prevention within and beyond the kidney health community and promote awareness of such methods to the general public and finally foster education and training in renal and related - particularly (cardio)vascular - diseases and therapies.

The five organizations that currently form the European Kidney Health Alliance are the following:

CEAPIR	<i>European Kidney Patients' Federation</i> (www.ceapir.org)
EDTNA/ERCA	<i>European Dialysis and Transplant Nurses Association/ European Renal Care Association</i> (www.edtna-erca.org)
ERA-EDTA	<i>European Renal Association – European Dialysis and Transplant Association</i> (www.era-edta.org)
IFKF	<i>International Federation of Kidney Foundations</i> (www.ifkf.net)
ISN	<i>International Society of Nephrology</i> (www.isn-online.org)

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COSMOS : A picture of CKD-MBD in the European Scenario

COSMOS (Current Management Of Secondary Hyperparathyroidism - a Multicentre Observational Study) is a study aiming to survey the bone mineral disturbances in hemodialysis population and the current clinical practice in Europe for the prevention, diagnosis and treatment of secondary hyperparathyroidism in hemodialysis patients.

The study design consists of a multicenter, open prospective cohort study collecting clinical parameters and outcome data from originally 5900 dialysis subjects from 295 dialysis centres in Europe in 21 countries.

This study is entirely noninterventional/observational and does not alter clinical management of subjects. Furthermore, all data are collected from medical records and does not require subject contact. The study will run for a duration of 3 years. Per individual subject enrolled data are recorded and collected every 6 months in a unique database regarding normal clinical practice, including markers of bone/ mineral metabolism, treatment variables and clinical outcome data (presence of co-specific mortality, CV-disease and/or bone disease, fractures, calcification, vascular access procedures). At the 6-month observation, markers of bone/ mineral metabolism that have occurred over the previous 6-month period will be recorded. Moreover, center-specific data are collected through a web-based data-base software.

Patient recruitment started in February 2005 and finished in July 2007. Patients recruited over this period of time were 4500 from 245 sites in 20 European countries. Approximately 80% of sites have already completed 2 years of follow-up, whereas almost 1/3 of sites have already completed the 3 years of follow-up.

The first preliminary data from COSMOS, based on 50% of the expected COSMOS study population, were presented for the first time at the ERA-EDTA Annual Meeting in Glasgow, July 2006 in a specific Symposium and also in three posters summarizing baseline COSMOS data. Initial evaluation of the baseline patient characteristics based on 50% of the expected COSMOS study population gives a useful initial insight into a broad dialysis population. There appears to be significant patient differences in BMI, Hb and serum albumin, biochemical parameters (serum Ca, Ca x P and iPTH) and incidence of parathyroidectomy, cardiovascular disease and calcification depending on time on dialysis. Most participating facilities follow specific practice guidelines; 63% of sites follow KDOQI™, 19% follow EBPG and 9% of sites follow national guidelines, however, the achievement of targets set out by KDOQI™ is far from optimal; only 9% of patients are within K/DOQI targets for all four bone parameters simultaneously (Ca, P, CaxP and PTH). The type of guideline being followed does not appear to affect patient bone mineral levels.

The first data on overall/cardiovascular mortality/hospitalization rate were presented at the ERA-EDTA Meeting in Barcelona, June 21st-24th, in a specific Symposium and in an Oral Free Communication. Data from 2495 patients that were followed up for 18 months were presented. Patients not achieving some of the classic bone and mineral K/DOQI targets (especially Ca above the target) showed an increased risk of mortality and hospitalization (All cause and cardiovascular-related).