

## President's Message

Dear Colleagues,

It is with great pleasure that I introduce you to our new and totally revamped quarterly newsletter. 2005 has been an exciting year for our Association with the launch of many new projects.



2006 will therefore be the year of change looking at always serving you better. Additional benefits are on their way such as the launch of the members-only section of the website including e-learning modules, a career centre, and many new features. We will also look at developing more partnerships with other organisations and work on constantly enhancing EDTNA/ERCA's profile.

We also look forward to the Madrid Conference and hope you will join us for an inspiring and stimulating event.

With warm regards,

*Althea Mahon*

Althea Mahon  
EDTNA/ERCA President 2004-2006

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## Disaster Relief in Pakistan

### EDTNA/ERCA Nurses and Technicians on the Ground

**Immediately following the October 2005 earthquake disaster in Pakistan, several EDTNA/ERCA nurses and technicians were onsite to lend critical aid to crush victims. Thanks to this prompt intervention, some 150 patients were provided with essential aid and treatment.**

The Renal Disaster Relief Task Force (RDRTF) is a unique humanitarian Task Force, created by the International Society of Nephrology (ISN), presently chaired by Prof. Raymond Vanholder from Gent University, Belgium. The RDRTF sends volunteer nephrologists, dialysis nurses and dialysis technicians out to offer help after earthquakes and other natural disasters by treating casualties with acute renal failure after crush syndrome (rhabdomyolysis). The RDRTF has at present 20 Belgian volunteers and 35 international volunteers mainly from EDTNA/ERCA and AFIDTN. The missions always take place under the steering and responsibilities of 'Médecins Sans Frontières' (MsF), Doctors without Borders.



### Aid in action

For the Pakistan mission, a scouting team consisting of 1 nephrologist/intensivist and 1 dialysis nurse was sent to Islamabad accompanied by people from MsF. This group arrived in Islamabad on 10 October 2005, they were soon followed by a second scouting team. The entire intervention lasted 23 days and in total, one scouting team and two full rescue teams were dispatched; in all 16 RDRTF volunteers (9 nurses, 5 doctors, 2 dialysis technicians) from four countries (France, Turkey, United Kingdom, Belgium).

On the home front, logistic and secretarial assistance for the dispatching of volunteers and goods was offered by a French and a Belgian coordinator for the nursing teams, as well as one contact person at MsF Belgium and one secretary at the Gent base.

In addition to this, extensive material support was also offered consisting of: 8 dialysis machines, 335 dialysers, 9 kg Kayexalate, 85 blood line sets, 30 central vein catheters and 6 paediatric peritoneal dialysis catheters. Several local dialysis machines which had broken down were repaired thanks to the contribution of our visiting technicians.

### On the ground

Peter Stockman, Technician at Dienst Dialyse (Belgium) and EDTNA/ERCA volunteer talks about his experience in Pakistan: "...At approximately 3 PM we arrived at PIMS. We were overwhelmed by the amount of casualties everywhere in the hospital... As the first machine was unpacked, the rest of the material was being disinfected and checked... At the end of the day all 4 machines were working and the next day we started with our Acute Renal Failure (ARF) patient programme". Stockman adds that it was essential that all machines be checked before being sent to Pakistan, and that it would have been almost impossible to rebuild some of the deficient machines without the support of a local dealer.

In total, 77 victims with ARF, were treated by dialysis in the broad Islamabad area, of whom 66 survived. In addition to the actual treatment, support and therapeutic advice was also given to at least



80 other crush victims without dialysis needs. At the end of the mission, 5 victims who needed dialysis treatment remained in Islamabad. Their therapy is now being taken care of by Pakistani colleagues.

*If you would like to get involved in such projects, please contact Jean-Yves De Vos, RDRTF link person for EDTNA/ERCA (devosjy@skynet.be).*

## Member Spotlight

### Maria Fettouhi Key Member Mentor



#### Why did you decide to join EDTNA/ERCA?

I have been a registered nurse for 9 years, working in nephrology since 1998. As nephrology was new to me, I was eager to learn more and hear about what was happening outside Denmark. I joined the Association at the Lisbon Conference (2000), where I met with peers from all over the world and learned a lot about nephrology. I was just sold to the idea that EDTNA/ERCA was a unique opportunity to help me in my career.

#### Why have you become an active member of the Association?

I joined EDTNA/ERCA after the Lisbon Conference, and became the Danish KM in December 2001. I was hunted for the position for over a year. Then I was invited to a training meeting with other new volunteers, and got support from former KMs. Although my first year was tough, I learned a lot from this experience.

#### What is your role in EDTNA/ERCA and the main challenges you are facing?

I was elected KMM in 2003, a big step... I didn't feel ready for that at all but everybody encouraged me to do it. My role as KMM is to train and support the national KMs around Europe, which can be challenging when communicating with many different cultures and languages.

#### Why would you encourage any members to become active in EDTNA/ERCA?

Becoming an active member of the Association gives you a broader perspective of the world of nephrology and the opportunity to meet many new friends. I have learned numerous things that I can still apply in my everyday job. I can only encourage more members to join our volunteer's team.

## What's New in EDTNA/ERCA

# The Collaborative Research Programme (CRP) Celebrates its 10<sup>th</sup> Anniversary!

**This year, the CRP is celebrating its 10th anniversary. Elizabeth Lindley the initiator of this programme, and Chair for the first six years, has performed outstanding work for which she received an EDTNA/ERCA honorary membership award at the AGM Birmingham Conference in 2003. As the programme's best ambassador, Lizzi shares her experience with us.**



The CRP Working Group

#### EDTNA/ERCA News: Why was the CRP launched?

**Elizabeth Lindley:** In the past, EDTNA/ERCA donated a percentage of the money earned from renting conference exhibition space to help fund the 'EDTA Registry'. The registry was established in 1964 and for many years it kept comprehensive records of dialysis and transplant patients across Europe. Problems with the Registry computer systems eventually led it to collapse in the mid 1990s. At the same time, our Executive Committee and the ERA-EDTA Council were unable to reach an agreement on the rights of EDTNA/ERCA members to access the Registry data. As a result, the Registry funding was withdrawn and the money was used to set up a programme to help our members in getting involved in collaborative research.

#### EDTNA/ERCA: What were the main challenges?

**EL:** The first problem we had was data management. We wanted to use an electronic data collection system and we were lucky to have Colin Aldridge (a former EDTNA/ERCA President) as a technical advisor. His company produced a user-friendly software package that allowed us to formulate and

distribute computer based questionnaires with on-line help.

Language was a problem too. With the budget we had for the project, it wasn't possible to produce the on-screen questionnaires in multiple languages, so we settled for providing phrase books with translations of the English questions and answers. Upgrades to Microsoft's Office suite mean that data collection forms can now be produced in Word, allowing for translation into any language and alphabet supported by Microsoft.

#### EDTNA/ERCA: What are the most significant results?

**EL:** From the very first project on management of vascular access, the exciting thing about the CRP projects has been seeing the wide variation in practice. Knowing that other units are doing something quite different to yours on an everyday basis can give you the confidence to try a change in practice. In this respect, every project has been significant.

For me, the most significant results so far came from the Water Treatment project. The findings of this study, which were presented at our international conference and at many national technical meetings, did a great deal to raise awareness of the need for effective control and monitoring of chemical and microbiological contamination. It led to the production of two sets of guidelines and I'm sure it helped many technicians to make the case for improved resources.

Another highlight was the second vascular access project, in which data >>>>



The Research Board in 2001

was collected for individual patients in order to link practice and outcomes. It produced some very interesting results, particularly on flow problems and infection in catheters. Unfortunately the changes in the requirements for ethical approval make this kind of study impossible to organise within EDTNA/ERCA, but I hope that the collaboration with DOPPS will lead to new research opportunities.

**EDTNA/ERCA: What have you gained personally throughout this experience?**

EL: The CRP Working Group, later to become the Research Board, was a really great team to be part of. Our meetings were very hectic so there was no time to be polite to each other. If someone thought your idea was crazy, they just said so. You couldn't afford to be too sensitive! But we'd break up at 19:00 and by 20:00 we'd be in a restaurant sharing stories and enjoying each others company. I

really appreciate the network of friends I made through the CRP.

Each project was an opportunity to learn - both about the subject, which was often outside my own expertise, and the statistical analysis. We were very lucky to have a professional statistician, Monique Elseviers, in the team. Perhaps the most important thing I learned was how to ask a precise question - it is so much harder than you would expect!

**EDTNA/ERCA: Why would you encourage other volunteers to take part in such projects?**

EL: Although projects with specific topics, such as paediatric access, are still organised, the backbone of EDTNA/ERCA's research programme is now the European Practice Database (EPD) project. I completed the EPD questionnaire for my centre when Northern England was surveyed. I enjoyed finding out how things were done in the sections of our service where I hadn't worked. And it was interesting to compare our practice with the rest of our region and the other EPD countries. I'd certainly encourage others to take part in the EPD and the topical projects. It does take some time, but it is definitely worth the effort - especially if you are interested in continuous quality improvement and practice development.

# Join the EDTNA/ERCA Volunteer's Team

**Vacancy on the EDTNA/ERCA Executive Committee (EC)**

If you are looking for a challenge, are committed and enthusiastic, then come and join us on the EC. We are seeking volunteers with leadership and management experience to be part of our team.

**Qualifications required:**

- Two years or more as a member of EDTNA/ERCA
- Good spoken and written English
- Working in renal care field
- Enthusiasm and organisational skills
- Ability to use computer and email
- Preferable that you have experience as a volunteer

**and more...**

The EDTNA/ERCA is also looking for volunteers for the following areas:

- Key Member - Hungary
- Key Member - Poland
- Anaemia IG - 1 member
- Paediatric IG - 2 members
- Social Workers IG - 2 members
- Transplant IG - 1 member
- Journal Editor
- English Co-editor

If you are interested or would like to recommend someone for one of the above position, please contact immediately Anna Öhrner at the EDTNA/ERCA Secretariat: 24 rue Chauchat, F-75009 Paris, France  
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International Conference Update

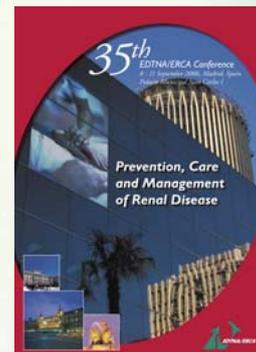
## Mark your Calendar!

### EDTNA/ERCA 35<sup>th</sup> International Conference

#### Prevention, Care and Management of Renal Disease

8-11 September 2006

Madrid, Spain



Papers will explore the following topics:

- Prevention or Delay of the Onset of Chronic Kidney Disease (CKD)
- Management and Care of Dialysis and Transplant Patients
- Infectious Diseases and Their Worldwide Expansion
- Open Forum

If you would like to submit a paper please visit: [www.edtna-erca-madrid2006.com](http://www.edtna-erca-madrid2006.com)  
Submission deadline: 20 February

A preliminary programme for the Conference will be mailed to you shortly.



The Conference President, Maria Cruz Casal Garcia, and the Local Organising Committee (LOC): Luis Martin Lopez, Isabel Delgado Arranz, Lucia Guerrero Llamas, Maria Luisa Fernandez Lopez, look forward to welcoming you in the magnificent city of Madrid!

To register and for more information, please visit: [www.edtna-erca-madrid2006.com](http://www.edtna-erca-madrid2006.com)

## Education Board Update

## E-learning: Education Board Looking at Future Educational Ventures

During the Vienna Conference, the Education Board (EB) members were involved in collaborative meetings with industry and other external agencies to discuss a range of potential future educational ventures. The importance of E-Learning as a philosophy for the delivery of education is now an important goal of EDTNA/ERCA. Judith Hurst is currently establishing plans for the successful implementation and the overall strategy of E-Learning.

Additionally, during the Vienna conference the Education Board also had the opportunity to facilitate a workshop on identifying the training needs of the EDTNA/ERCA Key Members (KM's) in collaboration with Maria Fettouhi, Key Member Mentor.

KM's have completed a specifically designed training needs analysis tool which builds upon both the job description of the Key Member as well as areas where KM's consider they require support.

Data from the KM survey is being analysed and it is hoped that the results will enable the EB to provide focused educational support in the future to the KM group.

*For more information about the EB activities, please contact John Sedgewick ([john.sedgewick@btopenworld.com](mailto:john.sedgewick@btopenworld.com)) or visit [www.edtna-erca.org](http://www.edtna-erca.org) (Education Board page).*

## Research Board Update

## Patients Now Able to Access Good Quality Information

Hans Vlaminc, Member of the Research Board (RB), has been busy developing a patient website which provides easy access and links to other websites containing valuable patient information. These websites have been evaluated in order to inform the user on where the best quality information can be located, this will hopefully save time for patients and staff searching through the plethora of information out there on the internet.

The RB is looking for patient volunteers to review information and judge the accuracy and quality of the information.

If you know any patients who may be interested in sharing their views, please get in touch with Paula Ormandy ([pormandy@aol.com](mailto:pormandy@aol.com)). Unfortunately the websites are all in English so an understanding of the English language is essential at this stage.

The members of the RB have a vast knowledge of research in practice and are only too happy to help any of the volunteer groups in developing research projects pertinent to their areas of interest. They are always open to suggestions and proposals for new and interesting projects from any member of the Association, so please encourage your colleagues to come forward and discuss research ideas. This way the developing research agenda within the Association will be able to fully address the needs of its members. A proposal form is available on the website for anyone who would like to respond, or you can send a short summary of your ideas to Maurice Harrington, RB Chair.

*For more information about the RB activities, please contact Maurice Harrington ([maurice.harrington@tiscali.co.uk](mailto:maurice.harrington@tiscali.co.uk)) or visit [www.edtna-erca.org](http://www.edtna-erca.org) (Research Board page).*

## Reach the Key Influencers!

The EDTNA/ERCA News, is the EDTNA/ERCA official newsletter published four times a year and distributed to some 4.200 individual members.

Showcase your products and reach the key influencers by advertising in this newsletter. For more information and to book your advertising space, please contact Anna Öhrner, Manager at EDTNA/ERCA Secretariat ([anna.oehrner@edtna-erca.org](mailto:anna.oehrner@edtna-erca.org))

## Calendar of Events

- ▼ **Nordiatrans**  
(Denmark Norway, Sweden)  
2 March 2006  
Copenhagen, Denmark
- ▼ **Annual Scientific Meeting**  
18 March 2006  
Athens, Greece
- ▼ **National Conference for Nephrology Nursing (HENNA)**  
25-28 May 2006  
Alexandroupoli, Greece
- ▼ **ANNA, 37<sup>th</sup> National Symposium**  
2-5 April 2006  
Nashville, USA
- ▼ **LDVT 6th Annual Conference**  
4-5 April 2006  
Veldhoven, The Netherlands

**For more information visit:**  
[www.edtna-erca.org/calendar](http://www.edtna-erca.org/calendar)



*Caring together*

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Would you like to contribute to the next issue? Please send your articles and pictures to Karine Desbant, EDTNA/ERCA Marketing and Communications Manager (E-mail: [karine.desbant@edtna-erca.org](mailto:karine.desbant@edtna-erca.org)).