

# Minutes of the ERA-EDTA National Societies' Meeting

ERA-EDTA and National Societies for Nephrology and Dialysis

June 12, 2019 – Corinthia Hotel Budapest

Room: Déry-Mikszáth-Jokai-Krudy in Valletta Centre I

## Participants:

Alberto Ortiz Arduán, Spain, Teaching and Research Coordinator

Andreas Kribben, Germany, President and Speaker

Andrej Skoberne, Slovenia, Secretary and AC for Central Europe

Andreu Foraster, Spain, President

Anibal Ferreira, Portugal, President

Annette Bruchfeld, Sweden, ERA-EDTA Council Member

Barat Yusubov, Azerbaijan, President

Bruno Watschinger, Austria, Secretary

Carmine Zoccali, Italy, ERA-EDTA President and Speaker/Moderator

Christoph Wanner, Germany, ERA-EDTA Council Member

Danilo Fliser, Germany, ERA-EDTA Renal Science Chair/Chairperson of the Administrative Offices and Speaker

Davide Bolignano, Italy, NDT-Educational@ENP Editor in Chief and Speaker

Dimitrios Goumenos, Greece, ERA-EDTA Council Member

Edita Ziginskiene, Lithuania, Board Member/Representative of the Registry

Elena Zakharova, Russia, Vice-President and AC for Central Europe and Speaker

Elnur Farajo, Azerbaijan, Editor of Medical Journal

Evgueniy Vazelov, Bulgaria, AC for Southern EU/Mediterranean Region

George Reusz, Hungary, President and Moderator

Giovambattista Capasso, Italy, ERA-EDTA Council Member

Giuliano Brunori, Italy, President

Goce Spasovski, Republic of North Macedonia, President

Gregor Guron, Sweden, President

Halima Resic, Bosnia-Herzegovina; President and AC for Southern EU/Mediterranean Region

Hani Hafez Mohammed, Egypt, President

Helle Thiesson, Denmark, President

Inga Bumblyte, Lithuania, President and AC (ERA-EDTA Activation Committee) for Northern Europe

Ivan Rychlik, Czech Republic, Past-President and ERA-EDTA Secretary-Treasurer

Jaroslav Rosenberger, Slovakia, Scientific Secretary and AC Chair for Central Europe

Kate Stevens, UK, ERA-EDTA Council Member  
Kristian B. Buhl, Denmark, Secretary  
Kristiina Kananen, Finland, President and AC for Northern Europe  
Loreto Gesualdo, Italy, Past-President  
Manuel Macia, Spain, Vice President and Speaker  
Maria Jose Soler Romeo, Spain, ERA-EDTA Council Member  
Marit Dahl Solbu, Norway, President  
Michal Nowicki, Poland, Past-President  
Peter Blankestijn, The Netherlands, ERA-EDTA Council Member and Speaker  
Raymond Vanholder, Belgium, Speaker  
Renathe Rismo, Norway, Board member/Secretary  
Saltanat Tuganbekova, Kazakhstan, Chairman of the Board  
Theofanis Apostolou, Greece, President  
Uyen Huynh-Do, Switzerland, President  
Viktorija Kuzema, Latvia, President  
Ziad Massy, France, ERA-EDTA Clinical Nephrology Governance Chair/Chair of the Registry

Staff for ERA-EDTA:

Bettina Albers, Germany, Press Office  
Monica Fontana, Italy, Executive Manager  
Monneth Briones Mascarinas, PA to the Executive Manager  
Sophie Bruno (Interel), Belgium – EKHA Secretariat  
Vit Borcany, PA to the Secretary-Treasurer

Apologies for Absence:

Aivars Petersons, Latvia, AC Chair for Northern Europe  
Andrzej Oko, Poland, President  
Choukron Gabriel, France, President  
Damjan Kovac, Slovenia, President  
F.J. van Ittersum, The Netherlands, President  
Frederic Collart, Belgium, Representative  
Graham Lipkin, UK, President  
Irma Tchokhonelidze, Georgia, President  
Joelle Nortier, Belgium, President  
Kyriakos Ioannou, Cyprus, President

Marie Mileine Couttenye, Belgium, President

Mladen Knotek, Croatia, President

Myftar Barbullushi, Albania, President

Sunna Snædal, Iceland, President

Venera Gjuka, Kosovo, AC for Southern EU/Mediterranean Region

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## **1. Opening and Welcome: Professor George Reusz (moderator)**

## **2. Presentation by the ERA-EDTA President, Professor Carmine Zoccali**

Professor Carmine Zoccali gave an update on the activities and initiatives of the ERA-EDTA.

- At the Congress in 2018, a paper was published by Prof. Zoccali in NDT with the title 'The ERA-EDTA today and tomorrow'. It described in some detail the organization of the association, which was briefly summarized by Prof. Zoccali at the meeting. The ERA-EDTA's organizational structure has been divided into two main sections: Clinical Nephrology Governance, and Renal Science Coordination and Administration. Led by Professor Ziad Massy as Chair, the Clinical Nephrology Governance section is now responsible for coordinating the ERA-EDTA Registry and the European Renal Best Practice (ERBP). The Renal Science section is headed by Professor Danilo Fliser, who is taking the lead of this important branch which will include the development of the ERA-EDTA Scientific and Educational Interaction Day (SEID), a new event organized by ERA-EDTA.
- This year in Budapest, the ERA-EDTA restructured the CME courses that are now called the Continuous Education and Professional Development (CEPD) courses. The Working Group-led courses have been replaced by a series of 13 brief educational courses covering the whole spectrum of nephrology, from Acute Kidney Injury and Chronic Kidney Disease to Clinical Epidemiology, Immunopathology, and Dialysis and Transplantation. These brief courses adopt a standard format, and each presentation will succinctly recapitulate established knowledge to form the basis for a review of new evidence accrued during the last two years. The aim of these courses is to create a clear, well-organized way for nephrologists to keep themselves updated on the background and the main advances in the various areas of nephrology.
- In Vienna this October, the ERA-EDTA will be launching a completely new event, the ERA-EDTA Scientific and Educational Interaction Day (SEID), where the various ERA-EDTA Working Groups will have an opportunity to interact

with each other with the aim of conceiving jointly conducted research projects. During the same event, short educational courses (proposed by the same Working Groups) will also be held. Overall, this new event will serve to integrate scientific knowledge and to facilitate the conception of clearly articulated and needed research projects to be submitted to funding institutions in Europe.

- The ERA-EDTA has conducted a survey in which over 800 nephrologists participated. Prof. Zoccali presented the key results:
  - More than 60% believe that dialysis centers will be increasingly owned by large private companies and that the majority of nephrologists providing care to dialysis patients will be employees of such companies
  - More than 40% believe that fully electronic clinical files will integrate the clinical ward, outpatient clinics, hemodialysis, peritoneal dialysis and transplantation.
  - More than 50% believe that personalized treatment of renal disease will be used more than it is now, but not dramatically so.
  - The great majority believe that more nephrologists will be needed for the care of stage 4-5 CKD patients in the future.
  
- ASN, ISN and ERA-EDTA have estimated the number of kidney patients worldwide (860 million). This 'wow' number may help to raise awareness. That number will probably continue to rise until 2040. Mortality, moreover, is high among kidney patients.

#### Discussion:

- Brief exchange regarding electronic files and apps – whether they are used in nephrology care in different countries (various experiences are shared).
  
- The question of how to recruit more nephrologists in the Medical Schools is then discussed. As another rise of prevalence is anticipated, more nephrologists will be needed. It was agreed that good education and research will attract young doctors

### 3. Reviving Nephrology: Testimonials

#### **Germany/Andreas Kribben**

The most important key to success in Germany is that there is only one major association representing all nephrologists (years before, clinicians used to have their own interest group, university nephrology theirs, etc.) By amalgamating them into a single association, the German Nephrology Society (Deutsche Gesellschaft für Nephrologie – DGfN), nephrology acquired a strong voice within the orchestra of different medical disciplines. The German Nephrology Society is open to all nephrologists, including those in the Pediatric Nephrology Society. Prof. Kribben gave a detailed overview on the German nephrology 'landscape' and various projects that strengthen nephrology, such as certification programs, a common quality standard for

dialysis treatment, lobbying work, etc. The German society also addresses the manpower shortage, for example by initiating special mentoring programs for students and young doctors. The DGfN provides guidance to junior doctors in planning a successful program in which outpatient care and hospital-based medical education are combined. Promoting nephrology among medical students is one main issue: Within the DGfN 'Get in touch' program, 80 medical students are invited each year to the DGfN Congress, where a 'Meet & Greet' as well as joint discussions are organized. They are not left alone, but are guided by experienced nephrologists.

### Discussion

- Prof. Ferreira: In Portugal, many young doctors want to become nephrologists. This may be due to the fact that young doctors have the option of doing research while they are working at the clinic. There are special research programs that allow this. Nephrology in Portugal is much more than just dialyzing patients. In Portugal, nephrologists perform kidney biopsies, implant catheters, perform imaging procedures, etc. The spectrum is broad and not at all narrow.
- Prof. Zoccali: Are hospital doctors in Germany involved in research, too? Or do they not do any research?
- Prof. Kribben: Research is only performed in university hospitals. But normal hospitals are involved in clinical studies, too, of course.
- Prof. Zoccali: Gene therapy is on the horizon. To ensure the survival of nephrological skills and knowledge, we need transformation. We should encourage the young to acquire special skills, for example in the gene therapy field. We need to expand our discipline.
- Prof. Kribben: All extracorporeal therapies are in the hands of nephrologists in Germany – including liver treatment and apheresis – and that could be extended to other countries also.
- Prof. Fliser: We certify our centers in Germany. The reason is the increasing level of cost for interventional therapies. Our politicians have therefore come up with rules and regulations (a transplantation center must transplant 25 kidneys a year, for example). The criteria and minimum numbers are often somewhat random, so the German Nephrology Society is responding by developing definitions of nephrological excellence centers before politicians could do so.
- Prof. Gesualdo: It is important to have homogeneous education in nephrology Europe-wide. As the European society, we should find a way to achieve this, otherwise nephrology will be totally different in different countries. How can this be done?
- Prof. Zoccali: I think it is important to defend nephrology, but it is difficult to harmonize the various systems. However, we can try and reach a situation where every nephrologist in Europe is able and has the knowledge to perform several services (e.g. fistulas, renal biopsies). This would secure a broad basis for nephrology everywhere.

### **Spain/ Manuel Macía**

Prof. Macia presents data on the Spanish Society of Nephrology (SEN). It has more than 2400 members and various working groups on a variety of topics, some of which

are not strictly nephrological, but interdisciplinary in nature (e.g. Onco-Nephrology, Geriatric Nephrology). SEN performs a wide range of educational activities, the most important being the Annual Congress attended by more than 1,200 delegates. SEN also operates a number of registries and awards more than € 300,000 a year in grants and scholarships. The Society has defined and adheres to a strategic plan based on four pillars: (1) strengthen the profession by increasing the passion for nephrology, (2) improve the prevention and treatment of CKD, (3) strengthen SEN as an institution by increasing its influence, and (4) strengthen SEN as a scientific society. The first milestones have already been reached.

- Prof. Kribben: We in Germany are struggling with registries. How do you handle this? Is it organized by a central platform?
- Prof. Macia: The main registries are organized by the transplant society. These relate to transplantation and dialysis.
- Prof. Kribben: One major problem in Germany is that we have no CKD registry, nor any dialysis registry. We try to exert some pressure in this regard, but with little or no success. We have small registries for special kidney diseases (e.g. Calciphylaxis), but no dialysis registry!
- Prof. Zoccali: Do you have enough nephrologists in Spain?
- Prof. Macia: We have the feeling that more nephrologists are needed, especially as the number of patients keeps growing, but the government came to the conclusion that there is no lack of nephrologists. Maybe they have failed to consider the whole body of data showing the increasing prevalence...
- Prof. Zakharova: Spain has the highest number of transplantations – what is the key to your success?
- Prof. Macia: The Spanish model is successful because of the enormous efforts we have made. First of all, any patient is per se a donor (opt-out model). Then we have special teams in the intensive care units who are specifically trained in communication and can talk to the relatives. The donor pool has also been extended. All this results in a high transplantation rate.

#### **4. Identifying educational needs at country level in Europe (Danilo Fliser)**

A JAMA paper showed that nephrologists treat the most complex patients with most comorbidities and with the highest risk of mortality. This means that nephrology is complex – as is nephrologists' training. Education varies between European countries, with different curricula, different forms of supervision and different examinations. This is why the ERA-EDTA has decided to concentrate on education, and especially the education of young doctors. From now on, it will be providing a broad range of educational activities, such as SEID and CEPD. The SEID (ERA-EDTA Scientific and Educational Interaction Day (SEID)) is a new event that aims to create an opportunity for face-to-face meetings to promote collaboration among Working Group investigators and to enlarge the educational portfolio of the ERA-EDTA. The first edition will be held on October 26, 2019, in Vienna, Austria. To identify the educational needs of the National Societies, Prof. Fliser conducted a live survey:

- Question: How can the ERA-EDTA help the National Societies to improve education? 30% believe that high-quality videos of selected presentations at the ERA-EDTA Congress would be valuable, 24% want the ERA-EDTA to send out educational material to the National Societies.
- Question: How important is ERA-EDTA as a partner in education? More than 70% of the respondents believe that it is important or even very important.
- Question: Would you like to have the ERA-EDTA more involved in education at the national level? More than 80% would like to see greater involvement.
- Question: In which areas are there educational needs? The top three topics named are: AKI and intensive care (19%), electrolytes & kidney stones (19%), glomerular and interstitial diseases (15%).
- Question: Which areas should be part of nephrology training? The top three topics named are: Transplantation and immunology (22%), renal pathology (16%), sonography & kidney biopsy (12%)
- Question: How do you rank the need for training in other subspecialties? The top three subspecialties named are: Oncology (24%), geriatric & palliative medicine (19%), cardiology (19%).
- Final Question for Discussion: How could the ERA-EDTA stay in contact with the National Societies regarding educational needs?

### Discussion

Prof. Fliser: Do some of the societies have a representative for education?

Prof. Macia: We have such a representative.

Prof. Reusz: I think it would be a great to find people in each country who are interested in this topic and then to connect them.

Prof. Fliser: Wouldn't it be handy if the ERA-EDTA had one specific contact person in each national society?

[general consent]

Then we will contact each society, ask for a contact person who is responsible for education – and we will connect and exchange ideas.

## **5. Involving young nephrologists in the life of the ERA EDTA. (Davide Bolignano and Andrej Skoberne)**

Prof. Bolignano gave a brief overview of the NDT-Educational@ENP webportal and related initiatives.

- NDT-Educational@ENP is the official educational eJournal of the ERA-EDTA with more than 6000 educational articles, including lectures, talk, and e-summaries from relevant congress talks.
- Newsletters which hint at new contents are sent out periodically.
- The portal offers interactive eDIALOGUES, too. 13 have already been posted to great response (146 total comments/replies).
- More opportunities for young nephrologists are on the way, e.g.
  - Medical student platform/Renal fellow forum.
  - ERA-EDTA call for expanding the NDT-Educational@ENP board.
  - ERA-EDTA Expert Opinion for Difficult Clinical Cases.

Prof. Skoberne provided information about a new initiative, the 'ERA-EDTA Expert Opinion for Difficult Clinical Cases'. This project is necessary because nephrology is all about rare diseases, high-quality care is based on experience, and experience is hard to come by. The idea is to prepare a list of experts with help from the National Societies. Two experts should be proposed by each national society for each topic (15 topics have been defined, from ADPKD to vasculitis). Young nephrologists will then have the opportunity to post a request for an expert opinion on ENP using a standardized request form. The request form will be sent to the email address of the administrator, who will then forward the request to the relevant expert and send back the "expert opinion". The expert would be expected to answer the request in two weeks.

#### Discussion

Dr. Soler: Sometimes one needs the information very urgently, two weeks is a long time...

Prof. Skoberne: You are right, but we had the feeling that we cannot expect the experts to answer within 24 hrs. Maybe we can reduce the time span to one week or establish a 'fast track'.

Prof. Zoccali: The ASN started a nephrology community discussion, and if asked, the best American experts are willing to give comments and explanations within a short time.

Prof. Skoberne: I hope we will experience the same. I honestly believe that the service will save lives.

Prof. Zoccali: it is advisable to involve Emeritus professors. They have the experience, the knowledge and the time.

Prof. Massy: The only barrier I see is the language. Not all speak and understand English.

Prof. Skoberne: I am afraid that there is not much we could do about this. We cannot afford a translation service; besides, it would take time.

The ERA-EDTA Council will further evaluate this proposal and will keep the National Societies informed.

## **6. European Kidney Health Alliance Working together to influence EU policy (Raymond Vanholder)**

EKHA's aim is to reduce the burden of kidney disease in Europe by defending the interests of kidney patients and the nephrology community at EU level and at national level. Prof. Vanholder describes the EKHA's structure and manner of operation. The number of associate members is growing, and it now consists of many European national and other non-profit kidney organizations.

As Professor Vanholder explains, EKHA takes action to raise awareness of the growing burden of CKD in Europe. It has developed the 'EKHA Recommendations for Sustainable Kidney Care'. To make sure the recommendations reach their audience and in order to increase awareness among EU decision-makers of the burden of CKD and to advocate for improved access to care and patient choice, special aspects of the paper were discussed at the EU Kidney Forum, EKHA's annual event held each spring in Brussels. The meeting is attended by delegates from more than 20 countries, including delegates from the European Parliament, the European Commission, the World Health Organization and national health ministries. EKHA has also established the MEP Group for Kidney Health. Another project is the 'Thematic Network: Improving Organ Donation & Transplantation in the EU', which will result in a joint mission statement.

To put it in a nutshell: EKHA is a multistakeholder NGO that defends the interests of kidney patients and the nephrological community in Europe and which strives for sustainable, high-quality kidney care for all. There are benefits of becoming an EKHA member, as Prof. Vanholder pointed out, e.g. National Societies gain fast and first-rate intelligence on what is happening at European level, are directly involved in EKHA's programs to influence European and national policy agendas regarding kidney disease, and have direct contacts in the European Parliament/Commission.

### **Why the Russian Dialysis Society is affiliated to the EKHA (Elena Zakharova)**

Professor Zakharova pointed out that EKHA membership has produced many benefits for the Russian Dialysis Society (RDS). It became affiliated to the EKHA in 2014. Since 2015, representatives of the RDS have attended the European Kidney Forum every year. The EKHA recommendations for sustainable kidney care – prevention and early detection, choice of treatment, and increasing access to transplantation – have been gradually implemented in Russia (but very slowly, unfortunately) and have brought about improvements in patient care. The international exchange is important and has resulted in greater awareness of kidney disease in Russia.

#### Discussion

Prof. Massy: Transplantation is always an attractive topic for politicians. What about prevention?

Prof. Vanholder: There are a lot of prevention projects going on, too. For example, in alliance with other chronic diseases we are trying to limit people's salt intake.

All National Societies were invited to become an active member in EKHA.

### **7. Green nephrology (Peter Blankestijn)**

The ERA-EDTA is the first medical association to try and implement 'greener' health care as proposed by the 'Lancet Countdown' group<sup>1</sup>, a collaboration among 24 academic institutions and intergovernmental organizations that tracks progress on health and climate change and provides an independent assessment of the health effects of climate change and the actions that are developed to stop it. The ERA-EDTA has already taken action on many fronts. Key points are:

- create awareness among members, an article has already been published in NDT. (Blankestijn PJ et al. Lancet Countdown paper: what does it mean for nephrology? Nephrol Dial Transplant. 2019 Jan 1;34(1):4-6. doi: 10.1093/ndt/gfy369)
- translate the general goals into specific activities within our field
- initiate, support and/or provide a platform:
  - for discussions with other stakeholders
  - for prioritization of areas to be addressed
  - for defining research questions

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1 Watts N et al. The Lancet Countdown on health and climate change: from 25 years of inaction to a global transformation for public health. Lancet 2018; 391: 581-630

- for creating tools / programs etc. to make sustainable healthcare education
- provide a platform for periodic reporting to the members, the general public and other stakeholders.
- organize its meetings in a 'green' way.

There have already been two meetings with the major industries – in March 2019 and at the Congress in Budapest.

Prof. Blankestijn conducted a survey among participants at the meeting:

- 100% believe that pollution/climate change have an effect on kidney health
- 100% feel that there is a need to discuss this topic
- 75% of the participants say that they have some kind of policy defined by their government with respect to the environmental impact of the health care sector.
- But only 25% state that such a policy has been defined by national healthcare organizations.
- 85% believe that their members are not aware of the damaging impact of nephrology on the environment.
- 88% believe that the National Societies have responsibility for informing about these issues.

(no discussion)

## **8. Live survey about the topics presented above and general discussion (Christoph Wanner)**

- 60% believe that having a single number (more than 850 million) encapsulates the epidemiological importance of CKD and may convince policymakers and health authorities that CKD is an absolute public health priority, but 25% believe it is not useful and even confusing, because it combines CKD with AKI and ESKD-dialysis and renal transplantation.
- 48% have so far not used the single number to lobby for CKD in their country, but intend to do so in the near future.
- 55% say that in their country, nephrology units have an insufficient number of nephrologists (45% say it is sufficient).
- 55% of those who said the number was insufficient say that this is due to underfunding and the unattractiveness of today's nephrology.
- 50% believe that passing the European Nephrology Examination, set up by the UEMS, is a valuable achievement for nephrology trainees.
- 78% knew how many nephrologists took the UEMS examination last year.
- 61% believe that having passed the UEMS examination may be perceived as a valuable achievement in the individual curriculum of nephrologists.
- The UEMS examination has been officially adopted in Switzerland. Nevertheless, 55% do not plan starting activities/lobbying for a similar recognition in their own country, at least in the short to medium term.

## **Action points**

- (1) ERA-EDTA will stay in contact with the National Societies regarding their specific educational needs. To do this the ERA-EDTA will ask the National Societies for a contact person within each Country who is responsible for education – so as to start exchanging ideas on this very important topic.
- (2) The ERA-EDTA Council will evaluate the proposal of establishing the 'ERA-EDTA Expert Opinion for Difficult Clinical Cases' platform and will keep the National Societies informed.
- (3) The ERA-EDTA encourages all National Societies to become an EKHA member.
- (4) ERA-EDTA will inform the National Societies about steps which are taken and projects that will be started on "Green nephrology". The National Societies are asked to circulate this information among their members and, thus, raise awareness on the topic.

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**Prof. Reusz and Prof. Zoccali closed the meeting and thanked all the participants for the interesting discussions and lively participation.**