

ERA-EDTA National Societies´ Meeting / Protocol

June 2nd, 2017, Madrid, Spain

Participants:

Representatives of the National Societies

Alma Idrizi - Albania - Secretary General
Zheni Gjergji - Albania - Council Member
Karl Lhotta – Austria - President
Frédéric Collart - Belgium, BSN - Board Member
Vladimir Tesar - Czech Republic - President Elect
Ivan Rychlik - Czech Republic - Past President
Lisbet Brandi – Denmark - President
Mads Hornum - Denmark - Congress Secretary
Bo Feldt-Rasmussen – Denmark - Past President
Kadri Lilienthal – Estonia - President
Mai Ots-Rosenberg – Estonia- Past President
Christian Combe – France - President
Goce Spasovski – FYRM - President
Nikolina Smokovska - FYRM - Board Member
Mark Dominik Alscher – Germany - President
Andreas Kribben – Germany - Vice-President
Aikaterini Papagianni – Greece - President
Theofanis Apostolou – Greece - Vice-President
George Reusz - Hungary - President
Jozsef Balla – Hungary - Vice-President
Talia Weinstein - Israel - Past President
Loreto Gesualdo – Italy - President
Inga Arune Bumblyte – Lithuania - President
Asta Stankuviene – Lithuania - Council Member
Marina Ratkovic – Montenegro - President
Danilo Radunovic - Montenegro - Secretary
Jolanta Malyszko – Poland - Vice-President
Manuel Anibal A. Ferreira – Portugal - President
Damjan Kovac – Slovenia - President
Andrzej Skoberne – Slovenia - Secretary
Andreu Foraster - Spain, SEDYT - President
Inga Soveri – Sweden - Scientific Secretary
Turgay Arinsoy - Turkey - President

Bruce Hendry - UK – Past President

ERA-EDTA Council members

A. Wiecek - ERA-EDTA President

J. Fox - ERA-EDTA Secretary-Treasurer

M. Ketteler - ERA-EDTA CAO

I. Rychlik – Secretary Treasurer Elect

Z. Massy - Chair of the ERA-EDTA Registry

C. Zoccali - NDT Editor in Chief

D. Fouque - NDT Editor in Chief

A. Argiles Ciscart

M. Arici

GB Capasso

P. Evenepoel

D. Fliser

A. Ortiz

J. Malyszko

G. Spasovski

Further representatives/speakers

J. B. Cannata-Andia – Congress President

A. C. Ferreira - YNP Chair

R. Vanholder - EKHA President

M. Murphy - EKHA MC and President of EFKP

C. Wanner – ERA-EDTA Council Representative with the National Societies

ERA-EDTA Headquarters/Staff

M. Fontana, ERA-EDTA Executive Manager

M. Bieda, PA to A. Wiecek ERA-EDTA President

T. Petrová, PA to Prof Ivan Rychlík ERA-EDTA Secretary Treasurer Elect

Protocol

B. Albers, ERA-EDTA Press Office

1. Opening and Welcome Opening and Welcome: Andrzej Wiecek, Jorge B. Cannata-Andia (moderator)

2. Presentation of the ERA-EDTA President Andrzej Więcek/Activation Committees/FERA-Awards

Prof. Andrzej Więcek gives an update on the activities and initiatives of the ERA-EDTA.

- Prof. Więcek introduces all council members and mentions their additional functions, then he gives an overview on the top management and key personnel positions in ERA-EDTA.
- The number of the society's member is constantly growing, from 7,347 in May 2016 to 7,431 in May 2017.
- Congress Participation:
This year, 6400 delegates have registered so far. Most are from Europe, but 20% are from Asia. (final number of participants: 7,009). 59% of the delegates were from Europe, but nearly 20% from Asia, 8% from America (central & south & north)
- This year, most abstracts came from Spain (249 abstract), second-most from Japan (204 abstracts)
- Next congress will take place in Copenhagen (Congress president Prof Feld-Rasmussen), the congress 2019 in Hungary (Congress president Prof Reusz)
- Current activities of the ERA-EDTA
 - Working Groups (8)
 - Fellowship Programme
 - Research Programme (SAB)
 - ComIA
 - CME courses and CME Committee
 - Young Nephrologist's Platform (YNP)
 - Official Journals (NDT, CKJ)
 - Newsletters (Follow Us, ERA-EDTA Flash)
 - European Nephrology Portal (ENP)
 - Registry
 - European Renal Best Practice (ERBP)
 - Collaboration with International Societies (ASN, ISN, JSN, ESH, other)
 - ERA-EDTA Activation Committees (EACs)
 - Awards Committee
 - Ethics Committee
- Prof. Więcek gives an update on the ERA-EDTA Activation Committee: The aim is to involve every country to make European nephrology stronger. Some countries do not have representatives in ERA-EDTA Committees, therefore three ERA-EDTA Activation Committees (EAC) were formed and their chairpersons elected.
 - a) EAC for Northern Europe consists of the following countries: Estonia, Latvia, Lithuania, Finland, Norway
Chairperson: Prof. Aivars Petersons from Riga (Latvia).
 - b) EAC for Central Europe consists of the following countries: Slovak Republic, Slovenia, Russia, Georgia,
Chairperson: Prof. Jaroslav Rosenberger from Bratislava (Slovak Republic).
 - c) EAC for Southern Europe and the Mediterranean Region consists of the following countries:

Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Montenegro, Serbia, Kosovo, Egypt,

Chairperson: Prof. Petar Kes from Zagreb (Croatia).

At the ERA-EDTA Congress, a meeting with all three groups will take place. The idea is to ask the representatives of countries which are so far not active in the ERA-EDTA to name potential candidates for council membership and candidates for the chairpersons/speakers at the congresses.

- What does the ERA-EDTA offer to the National Societies?
 - The ERA-EDTA Grant is given to each European National Society. The society can choose a grant winner (Young nephrologists), who gets a three years free ERA-EDTA membership (including free access to NDT Online) plus one free Congress Registration to the annual ERA-EDTA Congress.
 - ERA-EDTA has a special section on its website that you could use to highlight special job/funding opportunities that your Society and/or institution, might have, thus giving a wide European visibility to this matter.
 - Topics that may be of interest to the European media can be brought to the attention of the ERA-EDTA Press Office by the national societies.

- EDITH project: The acronym stands for “The Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes” – and the project aims to examine the effect of differing kidney disease treatment modalities, organ donation and transplant practices on health expenditure and patient outcomes. The project is co-founded by the EU and ERA-EDTA, through its registry, is one of the project partners.
- 24 scientific events received an endorsement by the ERA-EDTA in the last three months (they can use the ERA-EDTA logo and are supported in marketing activities)
- The “Empowering Viral Hepatitis Elimination in CKD patients” initiative has been formed. The Foundation in charge of organizing this educational event, is led by Prof. Massimo Colombo, Chairman of the Board, together with a selection of internationally well-respected leaders in hepatology, public health, law and business. The Foundation’s Secretariat is hosted at the Campus Biotech in Geneva. Confirmed ERA-EDTA representatives in this initiative are: Prof. Salvatore Badalamenti (Italy), Prof. Michel Jadoul (Belgium), Prof. Nassim Kamar (France) and Prof. Annette Bruchfeld (Sweden)
- A special recognition is given by ERA-EDTA to reward persons who have been very active in the initiatives and life of the ERA-EDTA, as well as in the clinical and research fields regarding nephrology and its related subjects: the FERA (Fellow of the European Renal Association) recognition. The following ERA-EDTA members are now awarded as distinguished fellows (the selection method used was related to the strict requirements of FERA and was applied to the people present at the meeting): Professor Inga Bumblyte, Professor Mads Hornum

Discussion

Alscher: Are there any activities from the ERA-EDTA to enhance the positions of nephrologists in the hospitals (and the regulation of reimbursement)?

Wiecek: No, because ERA-EDTA is mainly a scientific association. But the question will be transferred to EKHA. In many countries there are less and less nephrologist and it is one of our aims to make our specialty attractive for young doctors.

Vanholder: EKHA acts mainly in the interest of the patients, less of the professionals. Besides, reimbursement systems are very different across countries, so it is very difficult to take actions.

Wiecek: But Professor Vanholder can provide analyses of costs. And that might be helpful for the national society for their individual negotiations with their reimbursement systems.

Massy: Yes, we need to have evidence: Therefore, we encourage people on national level to send their data to the ERA-EDTA registry.

Tesar: Concerning the activation committees: We do not know the individual nephrologists in the countries which are so far not involved in ERA-EDTA. A good way to come into contact may be the working groups.

3. Possible collaborations between YNP and the National Societies/Ana Carina Ferreira

- The Young Nephrology Platform was created in 2012: Its aim is to involve young nephrologists, trainees and scientists in all activities of the ERA-EDTA. aims to help young nephrologists in their careers. The challenge is to give educational material to young doctors and nephrologists; to help young nephrologists to improve their daily practice.
- The YNP has 251 members, mainly from Italy, Portugal, Spain and UK
- The YNP Board consists of 9 persons, who stay for 3 years, only the founding members stayed for 5 years.
- Ana Carina Ferreira/Portugal finishes her term as chairwoman at this congress, the new chairwoman will be Kate Stevens/UK.
- Activities: YNP organizes at least 1 CME course per year
 - Ana Carina Ferreira presents the opportunity of joint CME course to the National Societies: The national society of nephrology would have to publicize the CME among national members and officially endorse the course. In return they can name 2 persons for chairing sessions
- Advisory program: The program aims to support young professionals to built a successful career. The max length of the program is 1 year. At the moment, 32 advisors are active, but more are needed. Interested persons should contact Ana Carina Ferreira.
- A survey was performed to explore how YNP can support the National Societies. It showed that support is wanted in organizing meetings, CMEs, travel grants and literature.
- Ana Carina Ferreira suggests that National Societies could implement a YNP slot at their National Congresses. The idea would be to organize a small session, with 3 speeches of 15 min each delivered by 2 invited national members and 1 invited “foreign” member

Discussion

Alscher: We did not have the information. Would it be possible to get all the slides?

Fontana: Yes, all participants will be provided with the slides.

Reusz: The problem with young nephrologists at our congress is that, if they are talking to each other, they are in a small group – and it is not a formal session. So maybe YNP can find another solution to touch base with the young nephrologists of each country?

Ferreira: The country can choose the format. We are flexible and open to suggestions!

Gesulado: But the backgrounds of the participants are very different, because the educational programs are different in each country. This is a problem for joint initiatives. We had the same problem with the UEMS. Do not we need a task force to harmonize education?

Cannata: You are right! That has been an ongoing problem. Although progress has been made, one cannot expect fast changes. But for sure, we have to work in this direction – and the establishing of the European Nephrology Exam is a first step.

Goce: How about the budget? Who pays for the joint sessions?

Ferreira: Well, this can be negotiated. Our idea was that the two national speakers could be funded by the national societies and the foreign speaker by the ERA-EDTA.

Capasso: A problem is that the number of medical students interested in nephrology is decreasing. Therefore, we have the task to address more students, and not only the post-docs. I think it would be more successful, if the joint sessions were promoted by the YNP, because the national societies might not reach the target group.

Cannata: Give them an incentive. The Spanish Society of Nephrology has granted medical students free access to the congress.

Gesualdo: We need to implement more hands-on-courses in our congresses. This is what the very young want. Besides, we have to implement more internships during the study time. Young doctors should be invited to the national congresses; they might understand how exciting our specialty is. Thus, we might attract more young doctors to nephrology.

4. Cookbook for nephrology patients / Monica Fontana, Christoph Wanner

The idea is to create a cookbook for nephrology patients in collaboration with all the national societies. Because each national society has special recipes, which can be chosen. The cookbook will not be printed, but available online. All National Societies will collaborate and will be invited to send at least 3 local recipes. A group of 7 experts will prepare the scientific introduction.

- 1) Christoph Wanner (Germany);
- 2) 4 ERN WG members;
- 2) EDTNA/ERCA dietician;
- 3) ERA-EDTA President.

The Introduction will be in English (but it can be translated by the National Society) and the recipes will be in English and the national language. After Madrid ERN starts coordinating this project by forming the committee and deciding the steps with regard to the scientific introduction. Then, the National Societies start submitting their recipes. The aim is to present the cookbook in May 2018 at the ERA-EDTA Congress in Copenhagen.

Discussion

Wanner: I believe this is a very promising project, because nephrology and nutrition often go hand-in-hand. We have a nutrition working group – and the project is patient-oriented. I therefore hope that the national societies support this initiative!

Goce: Should these recipes be meant for patients (e.g. low phosphate etc.) – or is this just a collection of special European national dishes, regardless of their nutritional values.

Monica:

The idea was to combine both. The recipes should be suitable for CKD patients – but that can be discussed.

Murphy: You are right, this is a promising project. There was a cookbook for dialysis patients which was published a few years ago – and meanwhile it has been reprinted. This means there is a future in this!

Evenepoel (?): I would suggest that you add the nutritional facts to each recipes.

5. Fundraising and co-fund raising between National Societies and ERA-EDTA/ Ziad Massy

What is needed for a successful fundraising? First, an important and popular message has to be prepared (in the moment cancer or cardiovascular diseases dominate the fundraising “market”). Then, a very good marketing strategy has to be developed, involving the social media and other communication tools (both to give details about the program and for transparency reasons).

Actually, there are different ways to run a campaign:

- By volunteers during an annual Kidney week or World Kidney Day, but it needs thousands or millions of volunteers who support this campaign.
- By regular post or by use mobile/sms.
- By organizing specific events (Gala, or Renal Run).
- By crowdfunding which is an activity to collect money using an online platform. There are several websites where this activity can be done (all of them ask a fee to start the crowdfunding and a fee for each donation received).
- By hiring a fundraising agency that manages the campaign (for example the fundraising agency REAL works for Cancer Research UK).

The offer to national societies is that ERA EDTA could work as a facilitator between different national societies (with and without a fundraising program) to help them to construct if needed a National Kidney Foundation, and to find the best strategies at the national level to launch or to reinforce the fundraising policies (e.g. organizing a symposium at the next ERA EDTA meeting in Copenhagen to discuss these issues). ERA-EDTA can also help the National Societies reach a wider number of contacts (using the large database of emails that ERA EDTA have).

Being asked, if this would help the national societies, 11 positive feedbacks were given. Therefore, it was decided, that this issue would be discussed in Copenhagen next year.

Discussion:

Alscher: I believe, before discussing fundraising opportunities, we must think how to make kidney diseases more known and renal topics more attractive. We should brainstorm about this, we must know what messages we want to deliver.

Wiecek: What can the collaboration between the national fundraising and ERA-EDTA look like? The fundraising should take place on national level, but can be strengthened by the ERA-EDTA by putting a campaign on an international level.

Evenepole: An important aspect would be to involve patients as “embassadors”.

Murphy: We promote organ donation and raise 1 Mio a year. We sell flowers, but for sure, this is a local campaign and it would not work in every country. There is not one way of fundraising that works everywhere.

Cannata: The main problem is a logistic one – not every country has many volunteers who would do promotional work on the streets.

Massy: But for any campaign, a “sexy” message is needed.

Vanholder: Besides, we need a sort of “mapping”: There are countries without kidney foundations; we should know where the gaps are.

Hendry: Maybe one should involve a professional association, which aim at (1) private donations (2) corporate donations (3) legacies. Suitable messages could be “A transplant for all” or prevention of CKD.

Zoccali: The structure of the countries are different, but all have one thing in common: CKD is still perceived as a minor disease, we have to transport the message that CKD has an impact on society as diabetes or cancer. A slogan could be “Better shape” – targeting the connection between obesity and CKD.

Massy: Everyone is invited to think about possible slogans, so we can discuss the several suggestions next year in Copenhagen.

6. European Nephrology Exam/Jorge B. Cannata-Andia

The Harmonization of Training in Nephrology in Europe is an important goal of UEMS and ERA-EDTA. Therefore, an international exam project was developed by the UEMS Renal Section and Board: Nephrologists of all countries are now able to take this exam, which has been adapted by the Royal Colleges of Physicians Exam (UK), and, thus, prove to meet the European standard. This European exam has to be taken in English and those who pass the exam get a European Certificate in Nephrology. The costs of the examination is 600 Euros. Of course, it is optional and does not replace the exam in the country the student comes from or has studied in. It is an additional qualification, which could help nephrologists to find a job in another country. The first European Exam was taken on 1st March, 2017, in many European cities; 77 young nephrologist from 19 countries sat to it and 44 passed it. A survey showed that nearly 70% of the participating young nephrologists heard of the exam via their national society. Thanks for the promotion and keep on spreading the word!

Discussion

Cannata: We encouraged Nephrology Associations to discuss the idea of including this high-quality examination in the national training scheme assessments (as Switzerland might do). Are some national presidents thinking about adapting the exam in their country?

Alscher: In Germany, taking the exams are a complex process and nephrology has no influence. Therefore, it is rather unrealistic!

Combe: Similar with us in France. The exams are taken centralized on a national level. Including this examination in the national training scheme assessments would be very difficult.

Cannata: Actually, the aim of the exam was not to replace the national exams, but for some country, it might just fit in.

Ferreira: In Portugal, it cannot substitute the national exam, either it is an additional qualification. Doctors have then the advantage to move to and work in other countries. Apart from that, I am happy about the good results of the Portuguese nephrologies – all our doctors passed the exam!

Evenepoel: How about the fee of 600 EUR? Might that be an obstacle?

Cannata: The real costs are even higher (800 EUR) – but we could offer a discount of 200 EUR. We suggested to the national societies to invest some money in it, e.g. paying the fee for promising candidates.

Reuzs: An idea would be to “sell” the exam to European authorities and get it refinanced in this way.

Zoccali: One could easily introduce and implement the exam in 2-3 universities, we should take the initiative!

Kribben: It depends on the textbooks the students work with. If they are not in English they will face difficulties with the exam.

Wiecek: I would like to stress that the exam is a very good initiative. It took a lot of work plus time to prepare and we are grateful that Professor Cannata initiated this project successfully. By the way even one council member sat the exam (Alberto Ortiz) and passed – congratulations!

7. Live survey/ Christoph Wanner

Professor Wanner performs two live surveys about the European Nephrology Exam and the role of the nephrologists in Europe (see the questions/answers enclosed):

European Nephrology Exam - click [here](#) to see the survey and the results.

The role of the nephrologists in Europe - click [here](#) to see the survey and the results.

Discussion

Evenepoel: ERA-EDTA has the mission to offer preparation courses for the exam.

Fontana: During the congress this could be done but the council is to make a decision about this.

Combe: Anyway, it is difficult to deliver the exam without any clinical practice. Only theoretical knowledge is being tested.

8. ERA-EDTA initiatives for National Societies/ Jonathan Fox

ERA-EDTA offers all National Societies many benefits (free of charge) aimed at enhancing their visibility and strengthening their role within the European nephrology community:

- There is a special section on ENP (European Nephrology Portal), where the National Societies have the opportunity to present themselves to an international

audience and promote their activities. Over the last year the National Societies' page on ENP received 1,444 visits.

- ERA-EDTA can help you with the promotion of an educational event and towards the cost of invited speakers.
- National Societies can exhibit at an important Congress with their National Society stand at the National Village.
- ERA-EDTA offers space in the National Village and complimentary registrations to the Congress
- ERA-EDTA offers the ERA-EDTA National Grant (with 3 years' Junior membership and free ERA-EDTA Congress registration)
- ERA-EDTA is happy to include information from your Association's in its official publications:
 - ERA-EDTA's official newsletter Follow us (Print and flipbook online) plus ERA-EDTA Flash (only online)
- ERA-EDTA is happy to include information from your Association's website and in its official publications and in the EKHA (European Kidney Health Alliance) bulletin
- ERA-EDTA offers a full page advert in Nephrology and Dialysis Transplantation (NDT)
- ERA-EDTA's Press office can assist your Society in communicating local health issues as well as investigator-initiated studies in your country on a European level.
- ERA-EDTA for patients and nurses special interactive sessions to enhance the learning experience and help with content retention.
- Other initiatives mentioned earlier (or later):
 - Activation Committees
 - Young Nephrologists' Platform (YNP)
 - Cookbook
 - Fundraising
 - European Nephrology Examination
 - Surveys
 - European Kidney Health Alliance (EKHA)

(no discussion)

9. **EKHA (European Kidney Health Alliance) survey on patient participation in decision making for renal replacement/ Raymond Vanholder**

EKHA is a strategic alliance of European non-profit organisations representing all key stakeholders in kidney health: patients, nephrologists, researchers and allied health workers – among them the ERA-EDTA. EKHA is a common effort by stakeholders to propose solutions for the challenges of Chronic Kidney Disease in Europe through effective prevention and a more efficient care pathway intended to facilitate the provision of appropriate and affordable treatment to all Europeans equally, while promoting the highest quality of care. Now, the EU launched a project to evaluate effectiveness and costs of ESRD treatment modalities (EDITH project). EKHA

Chairman Prof. Em. Raymond Vanholder presented the results of an online survey on treatment choices at the National Societies' Meeting (1 survey of patients and 1 survey for health care professionals to compare and contrast). The online survey had been

answered by 662 patients and by 460 healthcare professionals of eight European countries (UK, France, Netherlands, Slovenia, Lithuania, Spain, Greece, and Portugal). There might have been a bias, because the participants are obviously the ones who have internet access and are web savvy, and have time and interest in giving a response (for patients this means a representation more healthy patients). In summary, it showed that there was a substantial heterogeneity amongst countries. Besides, there was no country where all options of renal replacement therapy were proposed and explained to all patients. It seems that some sustainable options are not offered due to a lack of interest by the hospital/dialysis provider or due to the lack of specifically trained staff. Especially, the information on home dialysis was poor. Besides, living donation is often discriminated and conservative care is not offered to more than 85% of the patients. Often, the patients do not know about sustainable options, which results in a vicious circle (no patient information > no demand > no offering > therefore no patient information). In conclusion, financial drivers and lack of trained staff hamper free choice of treatment.

Discussion

Fox: Can the questionnaire be used by the national societies and/or individual centers? It might also be very informative, if the survey is conducted in individual centers. Then another question: Some patients are not informed about all options, if some of them would not be suitable for them. For example, you would not inform a 40 years old patient about conservative care.

Vanholder: Ideally, the patient should be informed about all treatment options. And I think, it would be possible to send the questionnaire to those who are interested in – and every can perform it on their national level or in his/her individual center.

Physician and Nurse Survey of Treatment Choice

Patient Survey of Treatment Choice

Kribben: How about the legal situation in the various countries? In Germany, the patient gets an information leaflet about the treatment choices and he/she must simply confirm that he/she has been informed by the doctor. It might even be legally binding in some countries.

Vanholder: As far as I know, there is no legal obligation in any country to inform about all treatment choices. What could national societies do about that? Many even give lots of information on the RRT on their websites already?

Combs: In a way, the results of the survey show that we have failed to inform our patients properly.

Vanholder: I think that the role of the nurses is underestimated. One could put the nurses in charge of patient information. The patients respects them and they find it easier to talk to them. By not allowing the nurses to do this job, we give away a big chance for a better patient information.

Wiecek: Closes the session.