

## **Minutes of the EKHA annual General Assembly 2022**

**DATE: June 15, 2022 / 11.00 – 14.00 CEST**

LOCATION: European Respiratory Society, 49-51 Rue de Trèves, Brussels

### **On behalf of the EKHA partners (with voting rights):**

EKHA: Raymond Vanholder (President, Belgium) RV (voting rights in case of a tie)

EKPF: Daniel Gallego (President, Spain) DG

ISN: Paul Laffin (Advocacy Director, Belgium) PL, delegated by proxy by Agnes Fogo AF

DKF: Tom Oostrom (EKHA Secretary, DKF CEO, The Netherlands) TO

EDTNA/ERCA: Ilaria de Barbieri (President, Italy) IB

ERA: Monica Fontana (Executive Director, Italy) MF delegated by proxy by Christoph Wanner

### **Attendants by Invitation of the EKHA partners**

EKPF: Jan van Cruchten (Secretary, The Netherlands) JC

DKF: Martin Ubbink (Public Affairs Advisor, The Netherlands) MU

EDTNA/ERCA: Edita Noruisiene (EKHA Treasurer, EDTNA/ERCA Past President, Lithuania) EN

EKHA Support Office: Eveline Scheres (General Manager, The Netherlands) ES

Serena Cristiani (EKHA support office) SC

Giulia Blancato (EKHA support office) GB

Greta Bitante (EKHA support office) – Minutes

### **Attendants on behalf of the EKHA affiliated members**

Dr. Drasko Pavlovic from Croatian Society of Nephrology. DP

Prof. Andreas Kribben past president of German Society of Nephrology. AK

Mrs. Tess Harris, President FEDERG. TH

Mrs. Fiona Loud, Policy Director of Kidney Care UK. FL

### **Attendants online on behalf of the EKHA affiliated members**

Ana Farinha (until 12:45), Portuguese Society of Nephrology

Elena Zakharova, Russian Dialysis Society

Halima Resic, Society for Nephrology, Dialysis and Transplantation of Bosnia and Herzegovina

Inga Aruné Bumblyté, Lithuanian Nephrology, Dialysis and Transplantation Association (LNDDTA)

Mai Rosenberg, Estonian Society of Nephrology

Marcin Adamczak, Polish Society of Nephrology

Mario Laganovic, Croatia Society of Nephrology

Marius Miglinas, Lithuanian Kidney Foundation

Edgar Almeida (joined 12:30 until 12:45), Portuguese society of nephrology

**Attendance online as observer**

Sandra Gaisch-Hiller, Baxter

Kilian Plus, Fresenius KABI

Pasquale Monteleone, Astrazeneca

Ondrej Vicklicky, Czech society of Nephrology

**Absent for the full partners:**

ERA: Christopher Wanner (President, Germany) CW

ISN: Agnes Fogo (President, United States) AF

**11.00 – 11.20: Welcome and Activity Reports**

RV opened the meeting and welcomed the attendees and presents the agenda:

**11.00 – 11.20: Welcome and Activity Reports**

- Adoption and approval of the agenda
- Presentation of Activities and Finance Accounts 2021
- Approval of new BoD member for EDTNA/ERCA, Ilaria de Barbieri
- Introduction of the EKHA Management Support team
- Re-election of the President
- Introduction of the President Elect Function

**11.20 – 11.25: Questions, Discussion and Discharge of the BoD****11.25 – 11.45: Achievements and running projects**

- Presentation of achievements of the first semester of 2022
- Achievements of the Working Groups
- Working program in 2022 and running projects

**11.45 – 12.00: EKHA affiliates membership**

- Membership fees as of 2023
- Questions and discussion to identify the wishes of the affiliate members and how EKHA can increase their support

**12.00 – 12.45: Introduction of new members and activities of other affiliated members**

- Belgium, Poland, Lithuania, Croatia, National Kidney Federation, Kidney Care UK
- Tour de table for updates from other affiliated members

12.45 – 13.00 EKHA's 15th anniversary

No remarks to the agenda presented and therewith approved by all partners.

**RV presented for information:**

- The expansion of the EKHA organisation since 2021 with:
  - 1 new full partner: ISN
  - 8 new affiliated members: Belgian Society of Nephrology, Croatian Society of Nephrology, Lithuanian Nephology, Dialysis and Transplantation Association, Kidney Care UK, National Kidney Federation, Polish Society of Nephrology, Czech Society of Nephrology, Latvian Association of Nephrology.
- EKHA also had meetings with Policy makers in 2021. These include EU Commissioner Stella Kyriakides, the Portuguese Deputy Minister for Health Antonio Lacerda Sales, the Director of the Commission Public Health directorate John Ryan and with the advisor of French Minister of Health Dimitri Grygowski.
- EKHA published an open letter on organ donation and transplantation launched on January 13th 2021.

- Call to action to improve CKD prevention, treatment and care in the aftermath of Covid-19 launched on February 26th 2021.
- On October 20<sup>th</sup> 2020, EKHA provided input to the expert panel for effective ways of investing in health on resilient health and social care. For this, EKHA had the support of two European parliamentarians, MEPs Pizzarro and Paulus.
- EKHA joined the American initiative, the Decade of the Kidney, launched by the American Association of Kidney Patients. The campaign was launched on March 11<sup>th</sup> 2021 at European level and aimed at boosting the innovation around kidney research.
- Annual Kidney forum event in June 2021 where policy makers and MEPs were present to discuss challenges in access to treatments in Europe. Response was published on Euractiv, Health Policy Platform, Politico Europe and Dods EU. The event had a good coverage on social media too, especially on Twitter and LinkedIn.
- An interview to EKHA President Raymond Vanholder was published on Politico in December 2021. EKHA also published a large number of papers in 2021-2022.

### For approval

- **Presentation of Activities and Finance Accounts 2021**

The Accounts of EKHA from 2021 were presented and approved by the partners and signed by the Executive Committee: Raymond Vanholder, Tom Oostrom and Edita Noruisiene.

- **Approval of new BoD member for EDTNA/ERCA, Ilaria de Barbieri**

EDTNA/ERCA has appointed the new president Ilaria de Barbieri. Thus, Ilaria de Barbieri needs to be approved as new member of the Board of Directors. Edita Nourisiene, now former president, will still remain on the board as an alternative representative.



**Approved by all partners.**

- **Introduction of the EKHA Management Support team**

EKHA is working with a new support team as of 2021 that was introduced for approval :

## Introduction of the EKHA Management Support Team

|   |   |  |  |   |
|---|---|--|--|---|
| <p><b>General Manager</b><br/>Eveline Scheres</p> <ul style="list-style-type: none"> <li>• Organisation management</li> <li>• Stakeholder management</li> <li>• Strategy</li> <li>• European calls</li> <li>• Working Group Coordination</li> <li>• Decade of the kidney program</li> </ul> |  | <p><b>Public Affairs Management</b><br/>Marine Faure –Senior Consultant<br/>Alicia Bé –Medior Consultant</p> <ul style="list-style-type: none"> <li>• Public Affairs actions and campaigns</li> <li>• European outreach to Commissioners, MEP's and relevant people in the EU political field</li> <li>• Content European Kidney Forum</li> <li>• Social Media Engagement</li> </ul> |  |  |
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|  |  |  | <p><b>Association &amp; Management Support</b><br/>Greta Bitante – Guilia Blancato –Serena Christiani</p> <ul style="list-style-type: none"> <li>• Financial Administration and invoicing</li> <li>• Mail</li> <li>• Minutes of (Board) meetings</li> <li>• Event coordination and logistics</li> <li>• Newsflashes</li> <li>• Support of EKHA President and General Manager</li> </ul> |
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The support team was approved by all the partners

### • Re-election of the President

Proposal for re-election for RV as EKHA President for an additional two years term 2022 -2024.

**Approved by all partners.**

### • Introduction of the President Elect Function

As of July 2024, EKHA would like to hold elections for a new president. Applications are open as of January 2023 and a final choice will be made by the EKHA partners before the GA of 2023 and the candidate will be presented there. After approval, the candidate selected will start as president elect in 2023, to become the president as of the GA of 2024. Raymond Vanholder will become as of then Past-President for a period of 1-2 years.

**Approved by all partners.**

### • Membership fees as of 2023

Approval was asked to make the following adjustments to the membership fees as of 2023:

- Adjustment of the affiliated membership fee as follows:
  - € 2625 >>>> € 2750  
for organisations with more than 500 members
  - € 1312,50 >>> € 1350  
for organisations with between 250-500 members
  - € 787,50 >>>> € 800  
for organisations with between 100-250 members
  - € 262,50 >>>> € 275  
for organisations with less than 100 members
- As of 2024 we will apply a yearly inflation correction (of max 5%) for affiliated members
- As of 2023 we will apply a yearly inflation correction (of max 5%) for the EKHA full partners.

**Approved by all full partners**

## 11.20 – 11.25: Questions, Discussion and Discharge of the BoD

The Board of Directors is discharged by the General Assembly.

## 11.25 – 11.45: Achievements and running projects of the first semester of 2022

### For information

- Introduction meeting MEPs – USA Kidney Caucus. It was decided to launch a declaration of intent in collaboration with the American association by the end of this year.
- Roundtable in Feb 2022 of experts in rare kidney diseases and MEP Pizzaro, patients and medical specialists to identify solutions to improve diagnosis, treatment and management of rare kidney disease. Official publication to go out this year.
- Update on the French Presidency of the EU. A workpaper has been published on defining a public health policy for the EU called “Draft Grenoble Declaration” in collaboration with the French Ministry of Health. EKHA managed to have several references to kidney disease entered in the text. EKHA is working very hard to encourage action on national representation level and to bring the issues from bottom to top as well.
- Update on Healthier Together Initiative, increased focus of the EU Commission on health issues. They are pushing for more to be done on policy level in the EU.

- World Kidney Day. It consisted in Awareness Raising Activities, which included video statements from EU policymakers and stakeholders, MEPs quotes and CKD patients' stories. An Infographic on kidney diseases was also used for the activities. The initiative was reported in Politico, Dods, Morning Healthcare.
- EKHA and Partners activities in Ukraine. EKHA developed several awareness raising activities as Ukrainian dialysis patients need water and electricity the delivery of which is often jeopardized in wars and it is right now a very problematic situation.
- EKHA participated in several webinars from the EC to discuss these issues.
- EU4Health – call for proposals on NCDs on CKD. EKHA also participated in a call for proposals on non-communicable diseases not included in the Healthier Together initiative with a focused on prevention and screening and increasing awareness. This proposal was submitted and now EKHA is waiting for the result.

#### • Achievements of the Working Groups

##### **Working group 1 on prevention and screening**

###### Research via a survey to:

- analyse existing screening programs in primary care in Europe;
- to understand the general attitude to – and use of – CKD detection/screening in GP practises;
- to evaluate the feasibility of screening for kidney disease

##### **Working group 2 on disease management**

Research for need and use of a Disease Management Toolbox, to provide kidney patients with a practical tool to better manage kidney disease in all stages. This tool should also be helpful to nurses, nephrologists, general practitioners and other specialists in supporting patients tackling their disease.

##### **Working group 3 on ground breaking innovation**

Collaboration to push for an international framework for new innovative and affordable Kidney Replacement Therapies (KRT's) in response to Horizon Europe's Strategic Orientations for Research and Innovation and the Advancing American Kidney Health (AAKH) Executive Order

#### **Questions from the affiliated partners**

AK, representative of the German Society of Nephrology thinks it is very impressive what has been done in finding support. What can the affiliated members do more actively to contribute to the EKHA goals?

RV says there are many points to be raised. It would be good if national societies copy EKHA's model to bring all stakeholders together. Secondly, it would be useful to talk to local policy makers about same issues such as raising awareness, avoid inequality, innovation and research. EKHA is calling upon national societies to involve them and is ready to help them with these goals at a national level.

MF adds that awareness is essential and this is indeed a team effort towards the final goal.

ES adds that all affiliated members can join in the EKHA working groups.

RV points out that in Scandinavia there are no members of EKHA and in Eastern Europe there are not many, so he encourages member societies to get in touch with them and get them involved with the cause.

PL adds it is important to raise awareness and encourage to get in touch with ISN to contribute in raising awareness.

ES adds that if societies have issues on national level which EKHA could try to resolve on a European level they should reach out to EKHA for support. RV adds that EKHA has a network of MEPs covering a lot of European countries that we can reach out to.

TO encourages affiliate members to embrace the decade of kidney strategy.

MF says that ERA have lots of material they can share and distribute.

DG says they would be pleased to connect to Swedish members to have members in the north as well.

FL comments about the collaboration necessary to reach goals and talking about infection level and huge cost of living affecting people and kidney patients. She underlines that it is important to share ideas and solutions from country to country and to consider the economic difference of people and what they can afford when comes to kidney diseases care.

No remarks from online audience.

- **Working program in 2022 and running projects**

Brief overview on the running projects working groups, other meetings, collaborations and events planned. Included in the presentation that will be attached as an appendix to these minutes.

### **11.45 – 12.00: EKHA affiliates membership**

- **Questions and discussion to identify the wishes of the affiliate members and how EKHA can increase their support**

Already discussed, please see paragraph: questions from the affiliated partners.

### **12.00 – 12.45: Introduction of new members and activities of other affiliated members**

1. Presentation from Dr. Pavlovic from Croatia illustrating the activity of the Croatian Society of Nephrology.
2. Presentation of Prof. Inga Arune Bumbylte, Lithuanian association of nephrology, dialysis transplantation LNDTA
3. Presentation from Prof. Andreas Kribben past president of German Society of Nephrology
4. Presentation from Mrs. Tess Harris, President FEDERG
5. Presentation from Mrs. Fiona Loud, Policy Director of Kidney Care UK

- **Tour de table for updates from other affiliated members**

### **12.45 – 13.00 EKHA's 15<sup>th</sup> anniversary**

Presentation of the 15th Anniversary of EKHA.

RV thanks everybody for the fruitful cooperation and invite them all to the European Kidney Forum of today.