



# Early Detection, Better Outcomes

Advancing Kidney Disease Screening in the EU

**28.01.2025**

15:30-17:30 CET  
Brussels, European Parliament, Room A3F383  
+ Online



# Agenda

15:30-15:40

## Opening Remarks

*Tamsin Rose (Moderator); MEP Tomislav Sokol*

15:40-15:50

## Testimonial: Experience from rare kidney disease patients

*Ms. Marianne Silkjær Nielsen, Founder, CompCure*

15:50-16:30

## Session 1 - Improving kidney disease screening in the EU

- The ABCDE model as a best practice for the EU – *Prof. Alberto Ortiz, Chair of the Registry and Renal Science; Chair-elect, European Renal Association (ERA)*
- Example of multistakeholder and cross-border collaboration with the PREVENTCKD project – *Ms. Eveline Scheres, General Manager, EKHA*
- Testing for CVD, diabetes, and kidney disease – Benefits of joint screening approaches – *Dr. Susan Connolly, Consultant Cardiologist, University Hospital Galway, Ireland; Ms. Elisabeth Dupont, Regional Manager, IDF-Europe*
- Q&A Session



**Acknowledgement of support:** The European Kidney Forum is made possible through the financial support of industry partners, including Astellas, AstraZeneca, Bayer, Baxter, B. Braun, CSL Behring, Fresenius Medical Care, GSK, Hansa Biopharma, Mozarc, Novartis, Novo Nordisk, Sobi, and Vifor Pharma.



# Agenda

16:30-17:10

## Session 2 - Policy Meets Prevention: What's Next on the Agenda for Kidney Health?

- Kidney health in past and upcoming EU presidencies – *Ms. Kitti Almer, Public Health Attaché, Hungary*
- Kidney disease on the global public health agenda – Benefits of joint screening approaches – *Dr. Valerie Luyckx, University Children's Hospital and Department of Public and Global Health, Epidemiology, Biostatistics and Prevention Institute, University of Zurich, Zurich, Switzerland*
- Looking ahead: Opportunities for kidney health in the new EU mandate – *MEP András Kulja*
- Policy recommendations to improve early detection – EKHA's wishlist to decision makers – *Mr. Daniel Gallego, President, EKPF*
- Q&A Session



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# Agenda

17:10-17:30

## Closing Remarks

*MEP Andrés Kulja*

*Prof. Raymond Vanholder, EKHA President*

18:00-19:15

## Networking Reception

*Venue: 12th Floor Restaurant, EP Spaak Building*



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# Opening remarks



**MEP Tomislav Sokol**  
(EPP, Croatia)



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# Testimonial: Experience from rare kidney disease patients



**Ms. Marianne Silkjær Nielsen**

Founder, CompCure



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**Marianne Silkjær Nielsen,  
Founder of CompCure,  
mother to 10 year old Esther**



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# Improving Kidney Health in Europe and beyond

Marianne Silkjær Nielsen  
Founder of CompCure





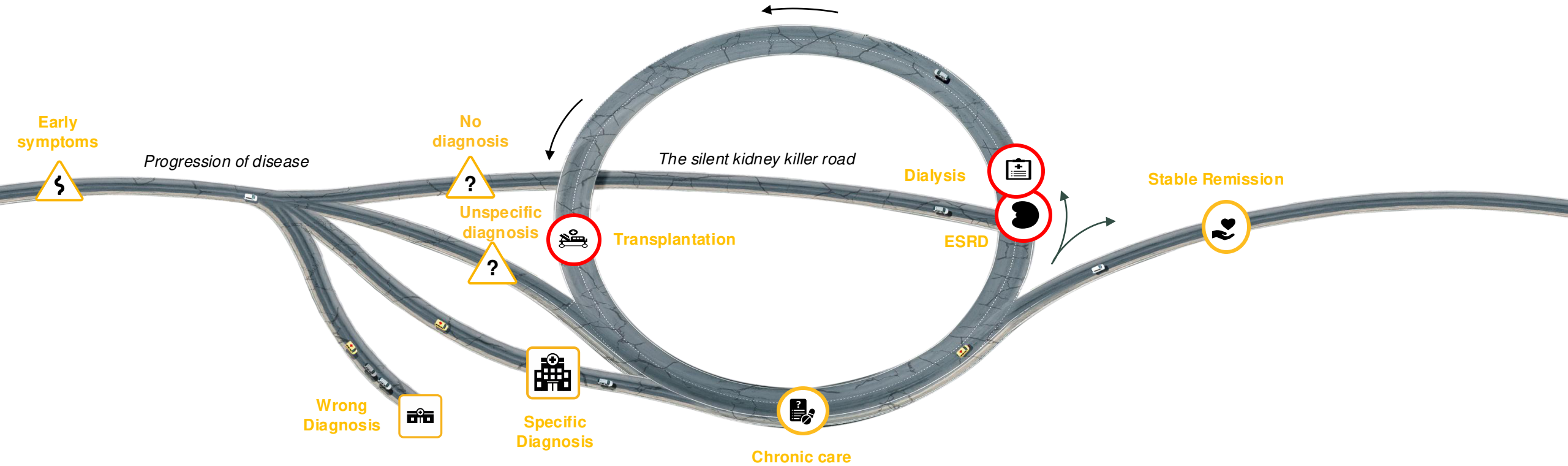
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***This situation is not unique, and it could probably have been avoided with an earlier diagnosis...***

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# The diagnostic journey is challenging for most patients



Source: Market research, April-August 2024

# We are more than our kidneys; we are also humans

Sick days  
Unemployment  
Financial issues  
Family problems  
Relationship problems  
Loneliness  
...

## Complications reported by patients and caregivers

**Nephrological:** Proteinuria, hematuria, inflammation, ESRD...

**Psychologic:** Stress, anxiety, depression, insomnia, disturbances...

**Neurological:** Headache, stroke, dizziness, pain, paralysis...

**Ophthalmologic:** Drusen, glaucoma, momentary visual impairment...

**Cardiovascular:** Hypertension, hypercholesterinemia, atherosclerosis, arrhythmia...

**Hematologic:** hypoalbuminemia, erythropoietin deficiency, sepsis...

**Immunological:** Multiple infections, adenoidectomy, tonsillectomy...

**Dermatologic:** Rash, eczema, pruritus, warts, molluscum contagiosum, stretch marks...

**Systemic:** Fatigue, edema, muscle cramps, general feeling of weakness...

**Other:** Impaired hearing, diminished appetite, nausea, pain, diabetes...



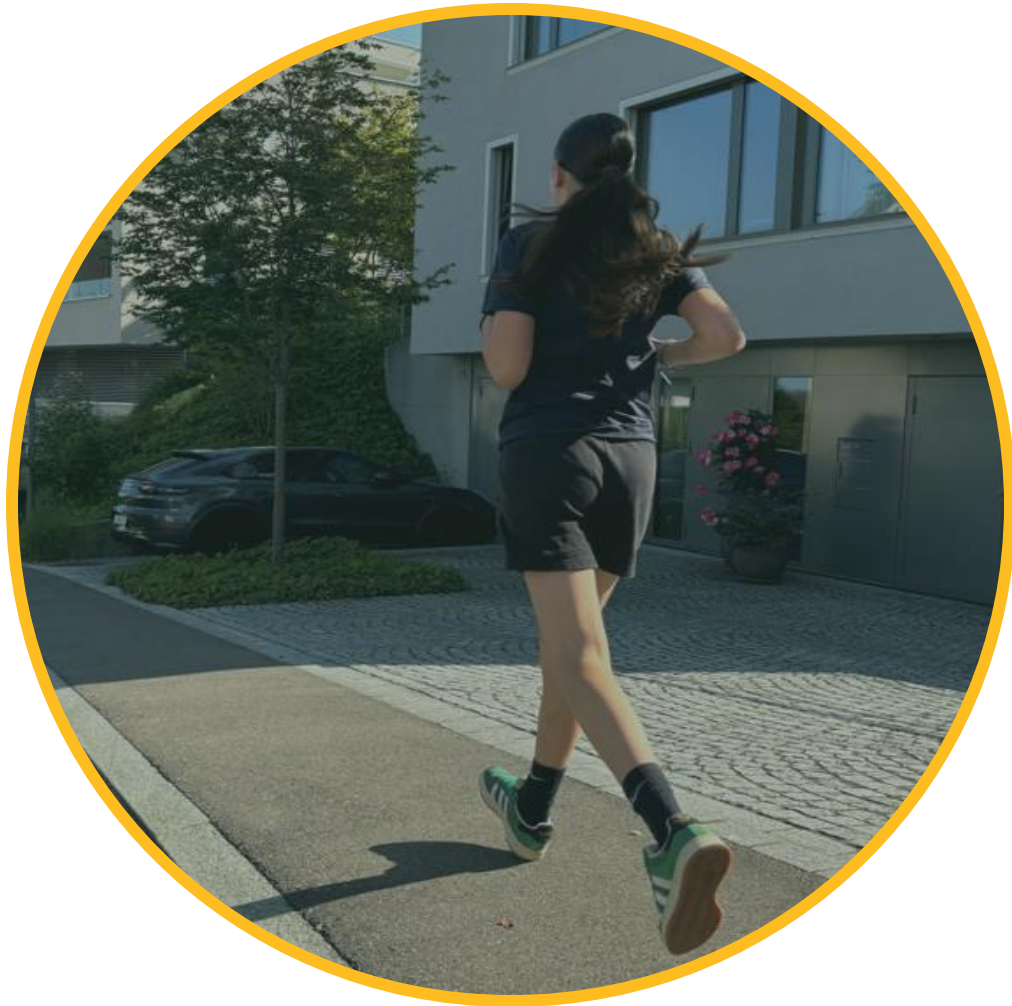
**Patient consensus  
summit, Brussels  
26-27 January**

**Patients and patients  
leaders from all over  
the world**

**Recommendations  
on how to improve  
kidney health**

# **Consensus on four asks on how to improve kidney health in Europe and all over the world**

- 1. Early detection of common and rare kidney diseases through broader screening programs**
- 2. Broader access to care through access to experts, access to medication, and access to trials**
- 3. Support people in dialysis to get transplanted through prevention of progression to ESRD and strengthened donation programs**
- 4. Prioritize kidney health in healthcare strategies and plans, to the benefits of patients, their families and society**



*Up to and after my diagnosis I felt so sick. I had to give up working. I did not even have energy to walk around the block....*

*...after I was enrolled in a trial and got access to a new therapy my energy came back. I could be the mother I used to be, start working again, and eventually run a marathon.*

Patient from Germany

A close-up photograph of two hands, one from the left and one from the right, positioned to form a heart shape. The fingers are gently curved towards each other, with the tips of the index and middle fingers meeting at the top and bottom. The background is a solid, bright yellow color. The text "Thank you" is centered within the heart shape.

**Thank you**

# Session 1

## Improving kidney disease screening in the EU



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# Early Detection, Better Outcomes

Advancing Kidney Disease Screening in the EU



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## Improving kidney disease screening in the EU



**Prof. Alberto Ortiz**

Chair of the Registry and Renal Science; Chair-elect, European Renal Association (ERA)



**Ms. Eveline Scheres**

General Manager, EKHA



**Dr. Susan Connolly**

Consultant Cardiologist, University Hospital Galway, Ireland



**Ms. Elisabeth Dupont**

Regional Manager, IDF-Europe



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# The ABCDE model as a best practice for the EU



## Prof. Alberto Ortiz

Chair of the Registry and Renal Science; Chair-elect, European Renal Association (ERA)



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European Society  
of Cardiology

European Heart Journal (2021) **42**, 3227 – 3337  
doi:10.1093/eurheartj/ehab484

**ESC GUIDELINES**

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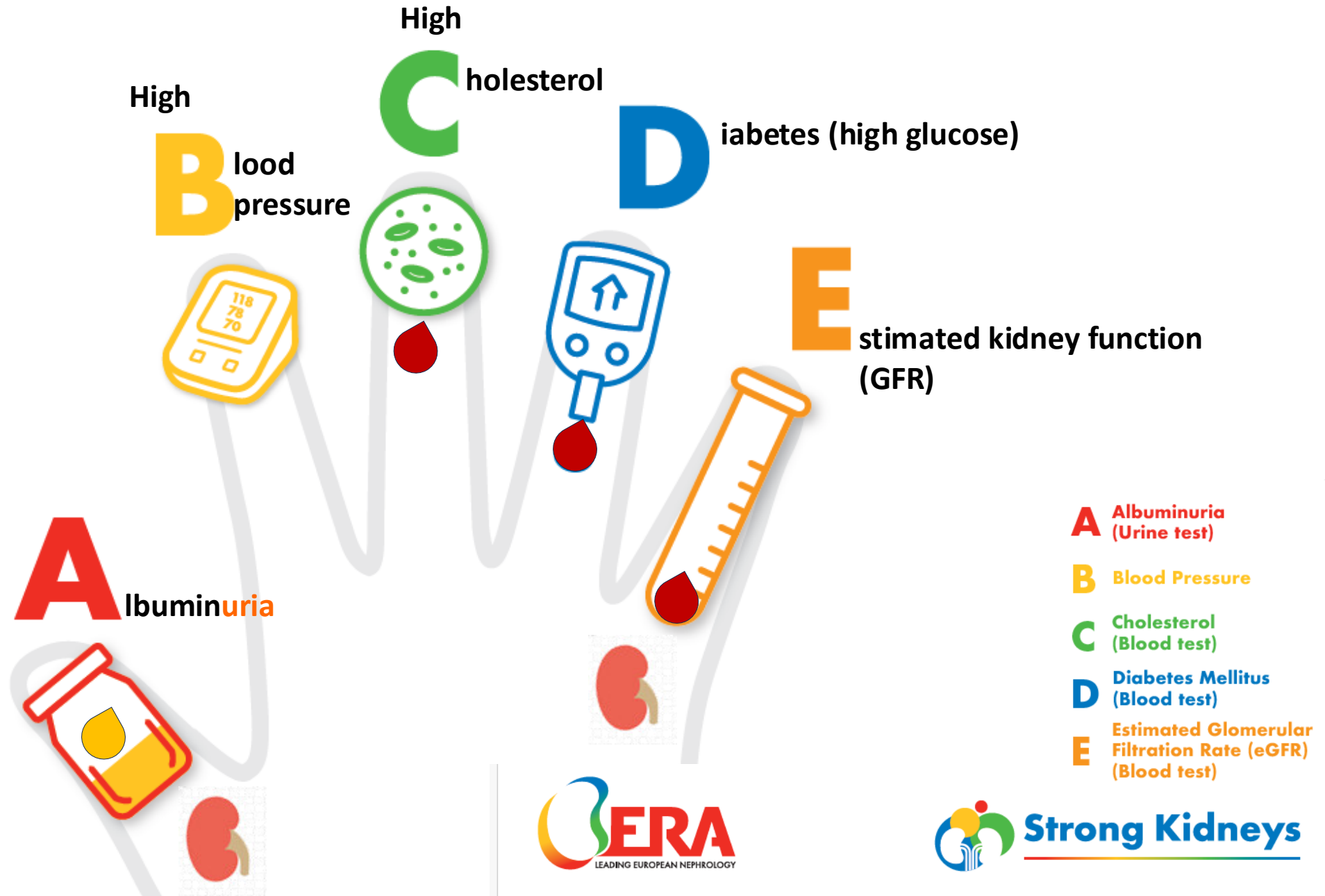
# **2021 ESC Guidelines on cardiovascular disease prevention in clinical practice**

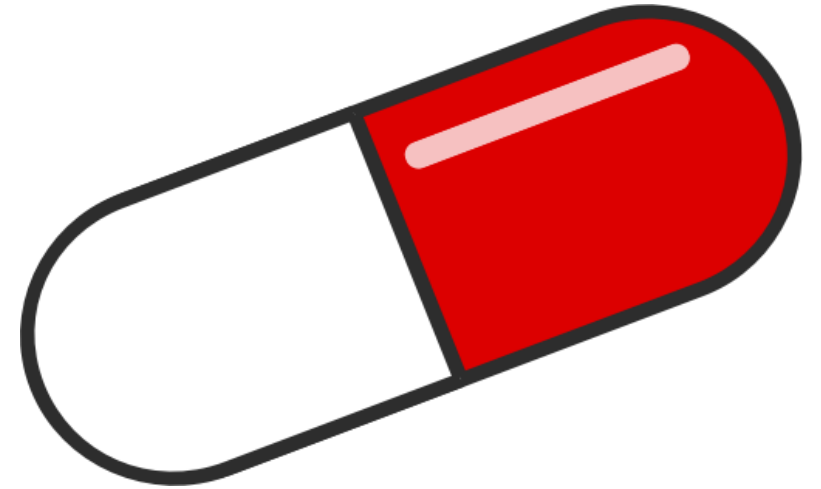
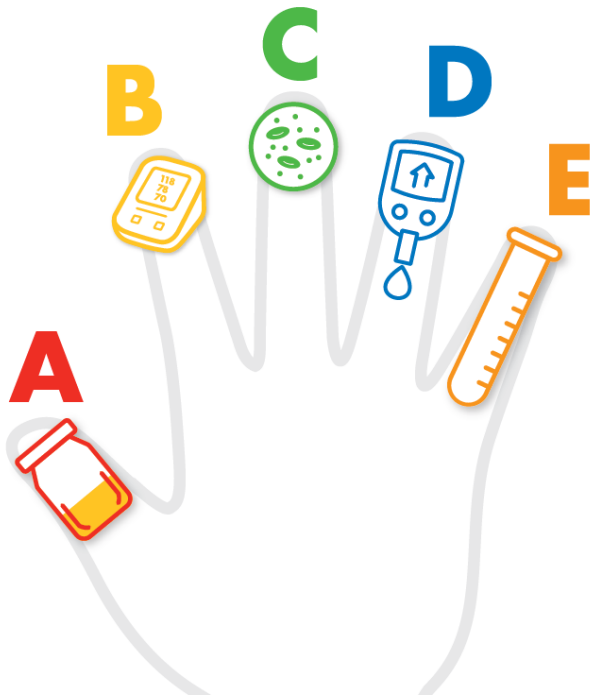
**Developed by the Task Force for cardiovascular disease prevention in clinical practice with representatives of the European Society of Cardiology and 12 medical societies**

**With the special contribution of the European Association of Preventive Cardiology (EAPC)**

# Know your ABCDEs

## Chronic Kidney Disease







Up to **5**



Different medications should be considered to decrease kidney and cardiovascular risk in people with albuminuria > 30 mg/g

**First**  
Kidneys get  
**injured:**  
High  
**Albuminuria**

**2030**

**A**



**B**



**C**



**D**



**E**

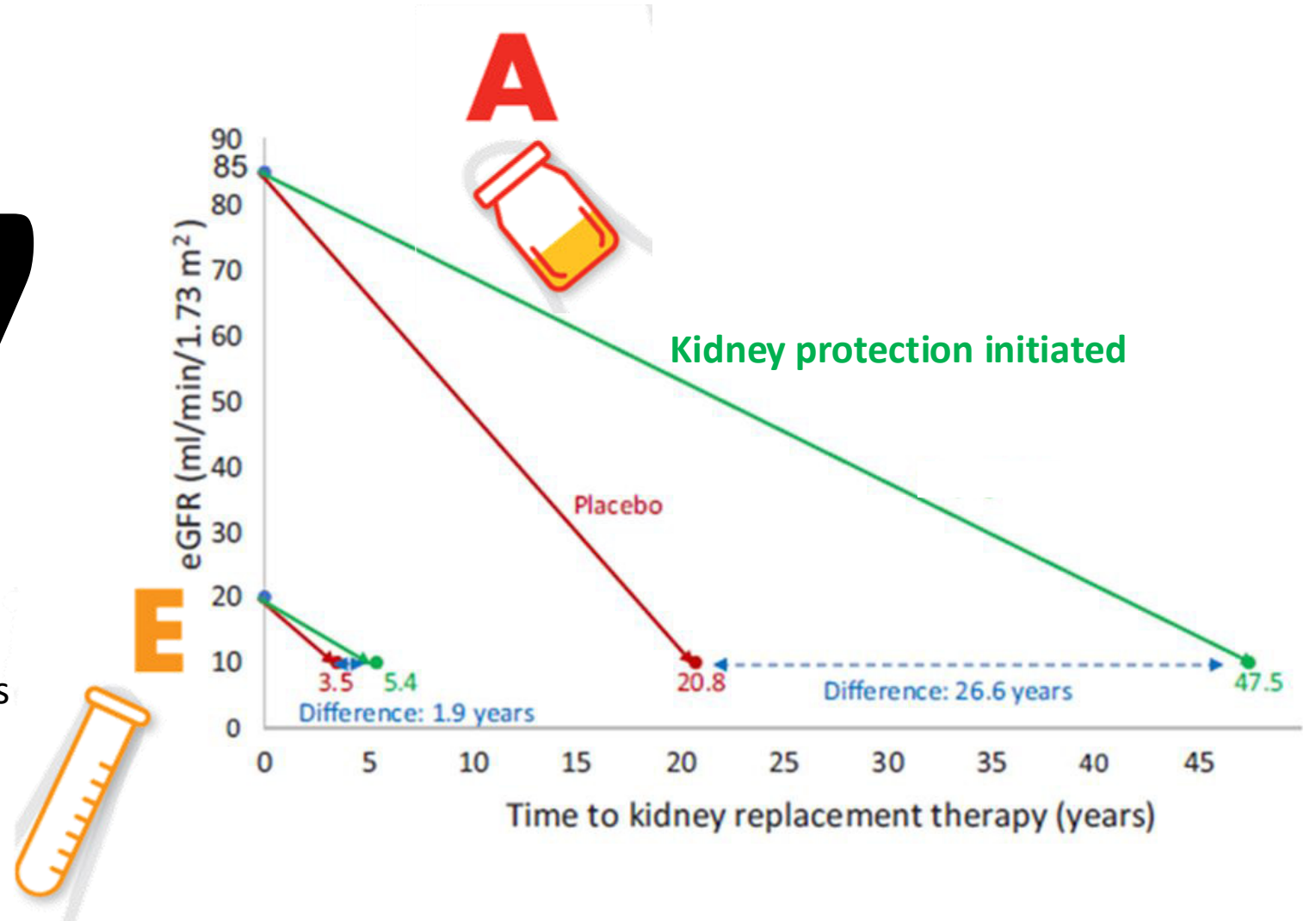


**Next**  
Kidney  
function is  
**lost:** low  
eGFR

**2025**

**Late!**

27 years



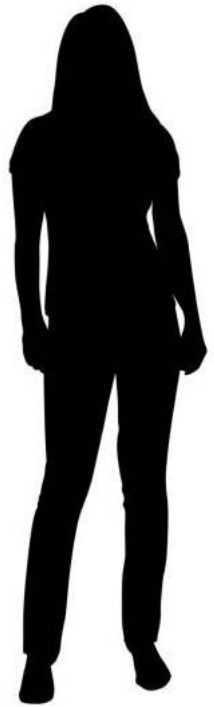
Hypothetical transformation of chronic eGFR slopes into time to kidney failure, defined as eGFR 10 ml/min/1.73 m<sup>2</sup>, in the EMPA-KIDNEY trial. Beatriz Fernández- Fernández, Pantelis Sarafidis, M José Soler, Alberto Ortiz. EMPA-KIDNEY: expanding the range of kidney protection by SGLT2 inhibitors. Clin Kidney J 2023;16(8):1187-1198



20<sup>th</sup>  
century

 44

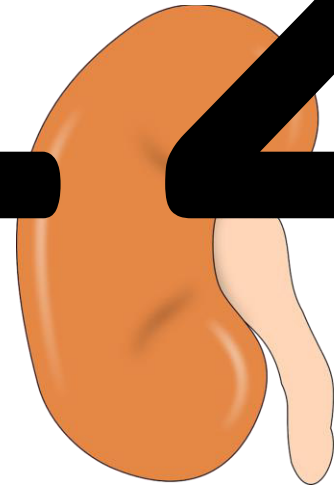
years





22

years





OCTOBER 2024

# SCREENING FOR CHRONIC KIDNEY DISEASE

Addressing the Gathering Global Storm

A Policy Paper from the Medical Advisory Council of the Global Patient Alliance for Kidney Health



## Know your ABCDEs

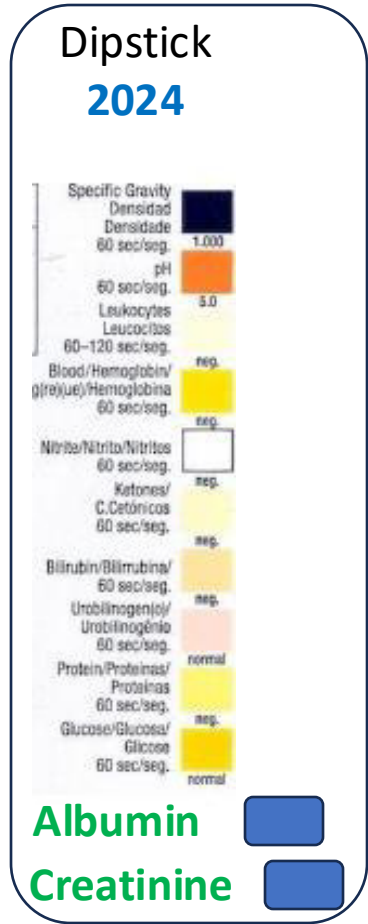
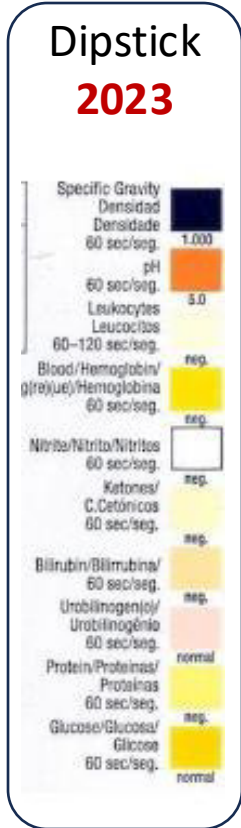
- A** Albuminuria (Urine test)
- B** Blood Pressure
- C** Cholesterol (Blood test)
- D** Diabetes Mellitus (Blood test)
- E** Estimated Glomerular Filtration Rate (eGFR) (Blood test)

**ERA**  
LEADING EUROPEAN NEPHROLOGY

**Strong Kidneys**

**Semiquantitative UACR in all urine samples for dipstick: quantitative UACR if above a threshold**

Doctor requests dipstick



Maria Salinas (Alicante)

Fully automated **semiquantitative UACR**

**Quantitative UACR** if **semiquantitative UACR** above certain threshold and no evidence of infection



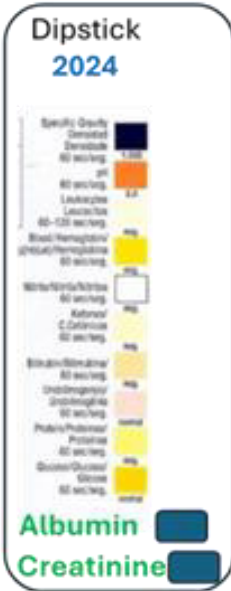
# Prevecolon 2024



# 50

years

# Prevekidney 2025



Community of Madrid



# Example of multistakeholder and cross-border collaboration with the PREVENTCKD project



**Ms. Eveline Scheres**  
General Manager, EKHA



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Advocates for kidney health



# SHIFTING GEAR IN CKD PREVENTION

**Eveline Scheres**

EKHA General Manager / Coordinator PREVENTCKD

**European Kidney Health Forum**

# PREVENTCKD



PREVENTCKD is a two-year project (March 2023 – March 2025, contract number 101101220) co-funded by the European Union.



The project specifically focused on the need for prevention and early detection of CKD.

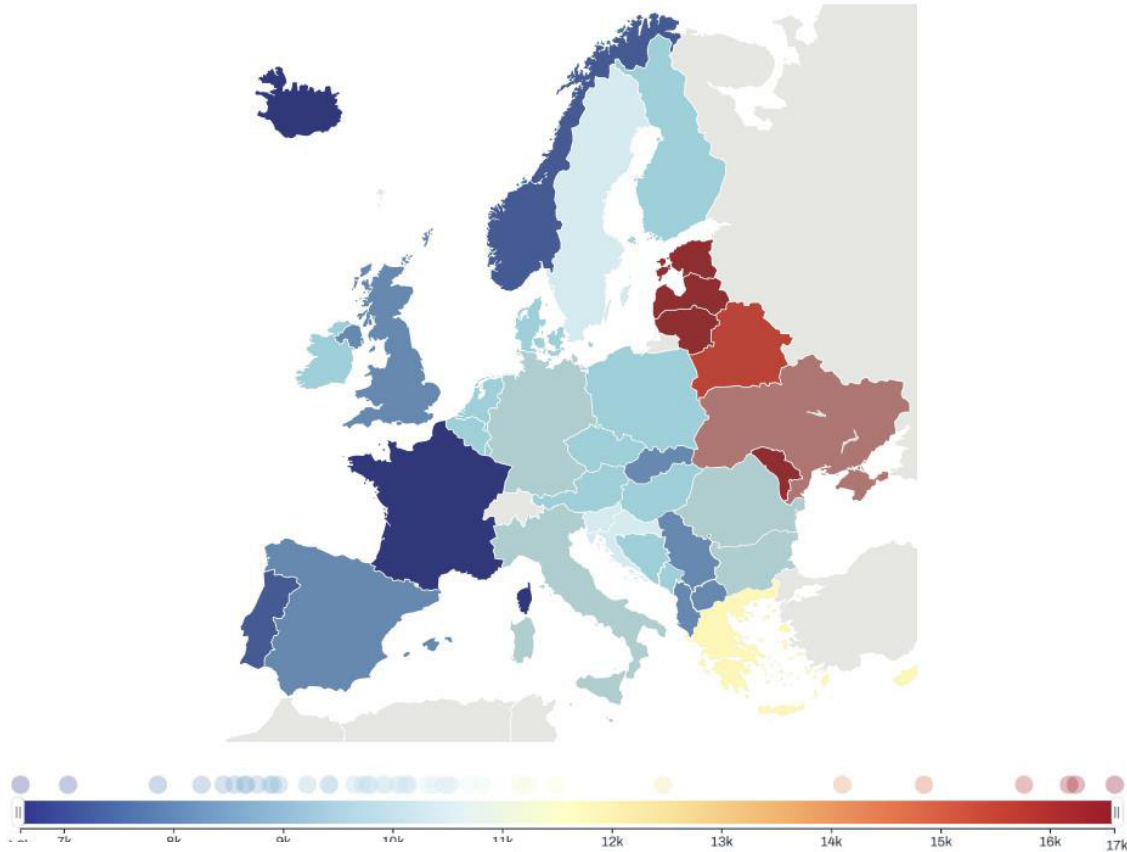


The project is an acknowledgement of the urgent need to create awareness for the high negative impact of Chronic Kidney Disease on people, planet and costs.



# PREVENTCKD - outcomes

*Increase awareness on the characteristics, implications and impact of CKD at EU population level and EU policy level.*




- Chronic Kidney Disease (CKD) is estimated to **affect close to 100 million people in Europe (>10%)**
- Over **0.5 million** individuals are on **dialysis** or living with a functioning **kidney graft**.
- **CKD prevalence is higher in Eastern than in Western European countries**, and there are heterogeneities in dialysis and transplant access.
- CKD is estimated to become the **5th cause of premature death by 2050**.
- More than **60% of the people** living with CKD are **unaware** of their condition.<sup>5</sup>
- The main **cause** of CKD is **diabetes mellitus**.
- The best **approach** for CKD is **prevention**.







# PREVENTCKD - outcomes

*Ways of preventing kidney disease*

**Especially in case of :**




**EARLY DETECTION**





-  Diabetes
-  Hypertension
-  Obesity
-  Age >50 years



-  Avoid toxics
-  Healthy food
-  Regular exercise
-  Hydration

**HEALTHY LIFESTYLE**



-  Education
-  Communication
-  Social support
-  Vaccination

**SELF-EMPOWERMENT**



-  Diagnostic tests
-  Visits
-  Diet
-  Treatment

**COMPLIANCE**

# PREVENTCKD - outcomes



*Ways of preventing kidney disease*

## European Kidney Health Code

**12** risk factors for chronic kidney diseases

### Lifestyle Choices, Biological and Social Factors

- 1 Unhealthy lifestyle
- 2 Age and gender
- 3 Harmful substances
- 4 Barriers to good health

### Kidney-Damaging Conditions and Diseases

- 5 Lifestyle-related chronic diseases
- 6 Prenatal & early life factors
- 7 Conditions affecting the urinary system
- 8 Living with one kidney
- 9 Acute kidney injury

### Kidney-Replacement Therapies

- 10 Treatment adherence
- 11 Waiting for a kidney transplantation
- 12 Kidney replacement therapy-related complications

The European Kidney Health Code provides information for healthcare professionals on actions individual citizens can take to help prevent Chronic Kidney Diseases.

**Successful prevention requires these individual actions to be supported by governmental policy and actions.**

# PREVENTCKD - outcomeEUtox

*Screening population at risk*

## SCREENING BASED ON GUIDELINES

Systematic cardiovascular risk assessment, including eGFR and albuminuria (ABCDE), is recommended in individuals with any major vascular risk factor, in men >40 and in women >50 years of age.

Visseren FLJ, Eur Heart J. g 2021 Sep 7;42(34):3227-3337.

## OPPORTUNISTIC SCREENING

Intelligent Lab automatically quantifies albuminuria when receiving a urine sample of a patient who should have albuminuria measured according to clinical guidelines, even if the doctor hasn't requested it.

## POPULATION SCREENING PREVE-RENAL

Systematic CKD screening program based on albuminuria assessment in a single urine sample in imitation to colon cancer screening program (stool test), although cheaper and non-invasive.

# Best Practices analysis



PREVENTCKD CONSORTIUM CONDUCTED THE INITIAL COMPILATION USING VARIOUS KEY TOOLS AND METHODS

- ### Sources for Best Practices
- EU BEST PRACTICES PORTAL
  - PUBMED
  - GOOGLE SCHOLAR
  - CONSENSUS AI
  - WEBSITES OF STAKEHOLDERS
  - PARTNER'S DATABASE

- ### Selection Criteria
- PRIMARY OR SECONDARY PREVENTION INITIATIVES ON CKD
  - EARLY DETECTION OR DIAGNOSIS INITIATIVES, INCLUDING POPULATION SCREENING ACTIONS, WITH PREFERENCE FOR THOSE THAT HAVE DEFINED THE RESULTS OBTAINED.
  - ACTIONS THAT WERE REPLICABLE IN DIFFERENT ENVIRONMENTS AND SITUATIONS.
  - STUDIES, CAMPAIGNS, INITIATIVES THAT COULD DEMONSTRATE IMPACT IN THEIR ENVIRONMENTS
  - ACTIONS THAT WOULD DELAY THE PROGRESSION OF CKD
  - EARLY EDUCATION INITIATIVES FOR CHRONIC KIDNEY PATIENTS IN THE INITIAL STAGES
  - IDENTIFICATION OF BIOMARKERS FOR EARLY DIAGNOSIS OF CKD
  - EARLY TREATMENT AND MANAGEMENT OF CKD

- ### Results
- THE 104 INITIATIVES WERE COMPILED INTO 6 GROUPS:
- GROUP 1: SCIENTIFIC RESEARCHES (RCT AND NON-RCT TRIALS) AND EDITORIALS.
  - GROUP 2: CLINICAL GUIDES, HANDBOOKS AND CONSENSUS PROTOCOLS.
  - GROUP 3: REPORTS, BIBLIOGRAPHIC REVIEWS..
  - GROUP 4: AWARENESS CAMPAIGNS, ACTIONS WITH POLICYMAKERS AND OTHER AWARENESS ACTIVITIES.
  - GROUP 5: EDUCATIONAL PROGRAMS, APPS, WEBSITES, BROCHURES, ETC.
  - GROUP 6: STRATEGIC DOCUMENTS, EPIDEMIOLOGICAL RESEARCHES AND OTHER ORGANIZATIONAL DOCUMENTS.



- ### Conclusions
- CKD HAS RISK FACTORS AND THE UNDERLYING DISEASES THAT CAN CAUSE IT
  - CKD HAS TWO VERY EFFECTIVE MEASURES TO CALCULATE THE STATE OF THE KIDNEYS: THE CALCULATION OF THE ALBUMIN/CREATININE/UREA RATIO AND THE ESTIMATION OF THE GLOMERULAR FILTRATION RATE.
  - TESTS DETERMINE KEY MEASUREMENTS ARE ACCESSIBLE TO PROFESSIONALS: A SIMPLE URINE ANALYSIS AND A SIMPLE BLOOD TEST
  - BOTH TESTS ARE VERY CHEAP AND AFFORDABLE FOR ANY HEALTH SYSTEM
  - LACK OF DATA ABOUT HOW PEOPLE IN RISK PERCEIVE THEIR RISK, HOW TO PROMOTE HEALTHY HABITS, FOLLOW THE MEDICAL RECOMMENDATIONS, PRESCRIPTIONS...
  - LACK OF CLEAR AND INTEGRAL GUIDELINES FOR HEALTHY LIFESTYLE
  - LACK OF DATA ABOUT HOW AFFECTS EMOTIONAL, COPING STILES, RESILIENCE ETC. IN ADHERENCE AND HEALTHY HABITS (NUTRITION AND PHYSICAL ACTIVITY)
  - LACK OF DATA ABOUT THE OUTCOMES IN AWARENESS CAMPAIGNS AND ACTIONS WITH POLICYMAKERS
  - LACK OF REAL DATA IN EARLY STAGES OF CKD (FROM STAGE 1 TO 4)



Stimulate health-management for people with kidney disease prior to the stage necessitating kidney replacement therapy.

Thank you!

[www.ekha.eu](http://www.ekha.eu)

 EKHA\_EU

 ekha-european-kidney-health-alliance

 info@ekha.eu



# Testing for CVD, diabetes, and kidney disease – Benefits of joint screening approaches



**Dr. Susan Connolly**

Consultant Cardiologist,  
University Hospital Galway,  
Ireland



**Ms. Elisabeth Dupont**

Regional Manager, IDF-Europe



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# Ireland's National Chronic Disease Management Programme (CVD, Type 2 DM, COPD/Asthma)



## Primary Care

800,000 patients registered

## 30 Community Hubs

1/150,000 Population

Opportunistic Case Finding (OCF) Programme

Primary Prevention Programme

Chronic Disease Treatment Programme

58%

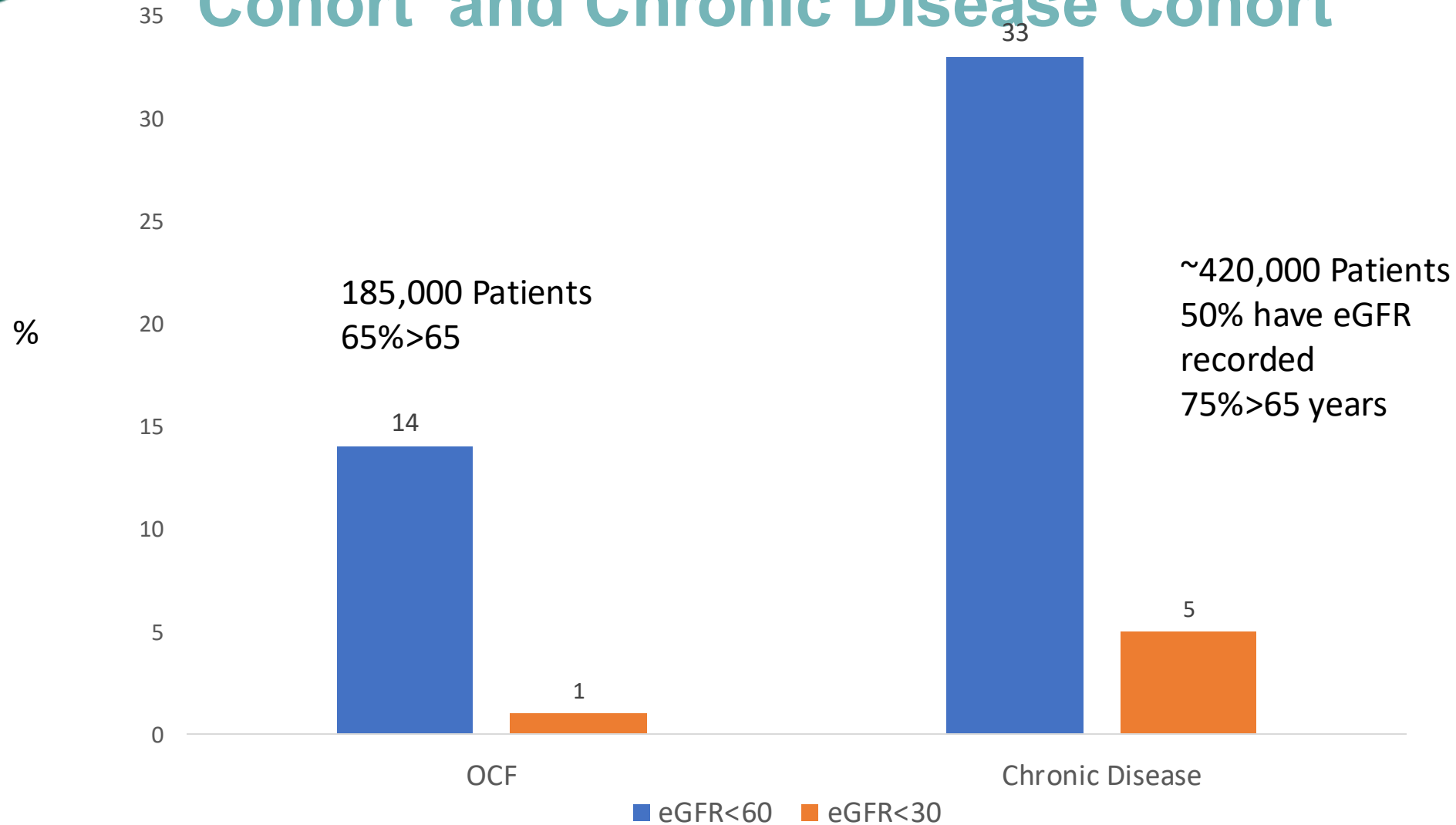
Consultant Led Chronic Disease Specialist Teams

Diagnostics e.g. ECHO

Cardiac & Pulmonary Rehabilitation  
Type DM Mgt



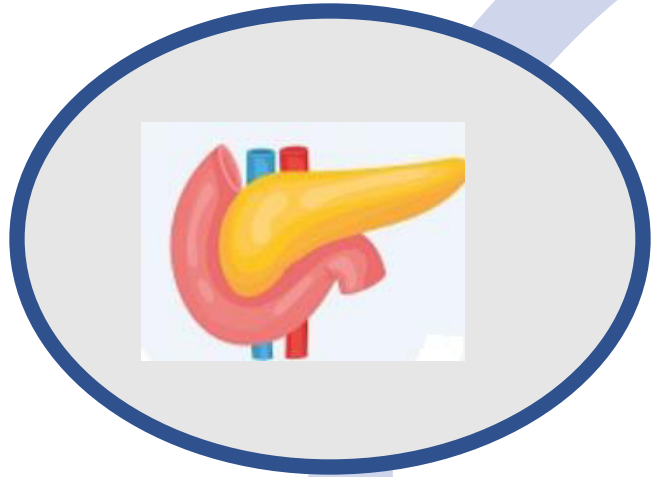
# Prevalence CKD in Opportunistic Case Finding Cohort and Chronic Disease Cohort



Data courtesy Dr. Orlaith O'Reilly, Lead HSE GP Chronic Disease Management Programme



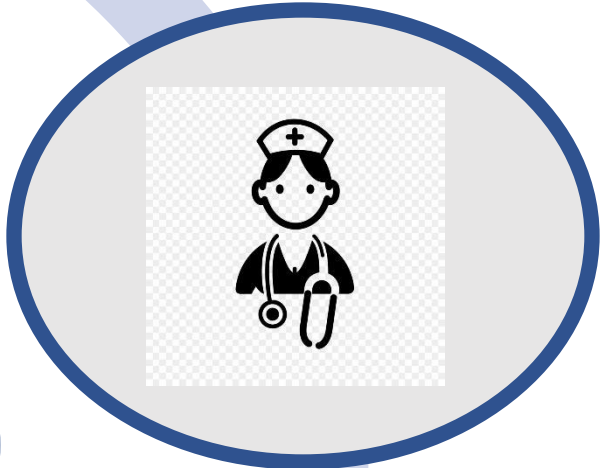
**Integrated Cardiorenalmetabolic Service**



# **Integrated Care Galway Hub**

Patients with  
Atrial Fibrillation  
Heart failure  
CVD  
Cardiorenalmetabolic  
Multimorbidity

**Nurse-led Education & Management**



**Cardiac Rehabilitation**



**Virtual/Remote Technology**



# Q&A Session



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# Session 2

## Policy Meets Prevention: What's Next on the Agenda for Kidney Health?



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## Policy Meets Prevention: What's Next on the Agenda for Kidney Health?



**Ms. Kitti Almer**

Public Health Attaché, Hungary



**Dr. Valerie Luyckx**

University Children's Hospital and  
Department of Public and Global Health,  
Epidemiology, Biostatistics and  
Prevention Institute, University of Zurich,  
Zurich, Switzerland



**MEP András Kulja**

EPP, Hungary



**Mr. Daniel Gallego**

President, EKPF



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# Kidney health in past and upcoming EU presidencies



**Ms. Kitti Almer**

Public Health Attaché, Hungary



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# Kidney disease on the global public health agenda



**Dr. Valerie Luyckx**

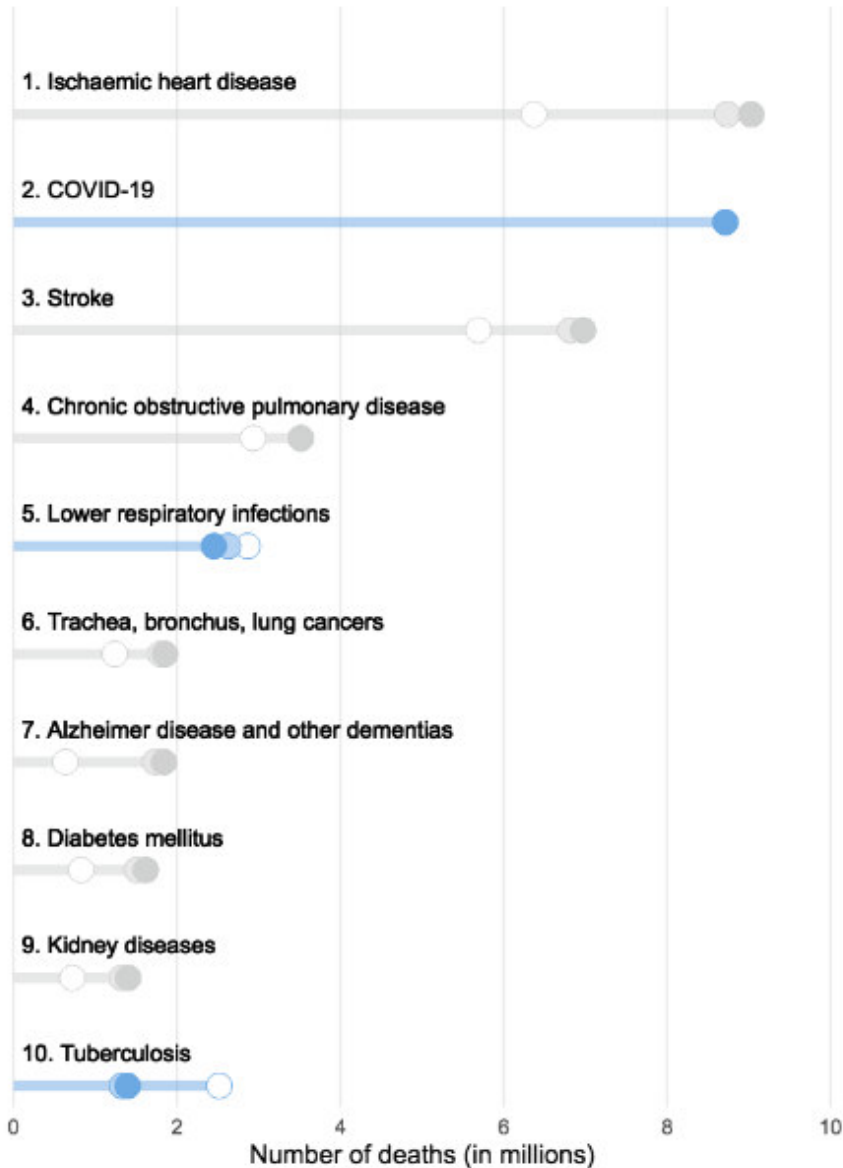
University Children's Hospital and Department of Public and Global Health, Epidemiology, Biostatistics and Prevention Institute, University of Zurich, Zurich, Switzerland



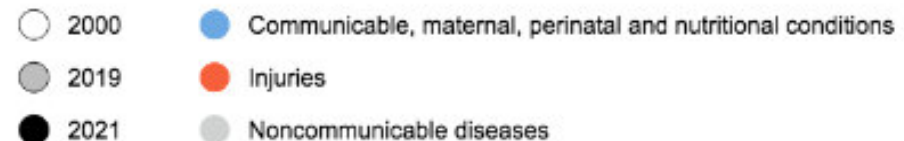
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# WHO: Top 10 global causes of death in 2021



“kidney diseases have risen from the world’s 19th leading cause of death to the 9th, with number of deaths increasing by 95% between 2000 and 2021”



# **Reducing the burden of non-communicable disease through promotion of kidney health and strengthening prevention and control of kidney disease**

**Draft resolution to be proposed by Guatemala.**

- The resolution aims to enhance prioritization of kidney disease on the global health agenda by calling for:
  - greater global awareness of Kidney Disease
  - education about, and promotion of kidney health
  - integration of diagnosis and treatment of chronic kidney disease into primary care non-communicable disease control pathways
  - health Systems strengthening to deliver sustainable, affordable, comprehensive and quality kidney care, especially in lower resource settings



# Looking ahead: Opportunities for kidney health in the new EU mandate



**MEP András Kulja**  
(EPP, Hungary)



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# Policy recommendations to improve early detection – EKHA’s wishlist to decision makers



**Mr. Daniel Gallego**

President, EKPF



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# Policy recommendations to improve early detection in CKD EKHA's wishlist to decision makers

*Brussels, Belgium January 28th, 2025*

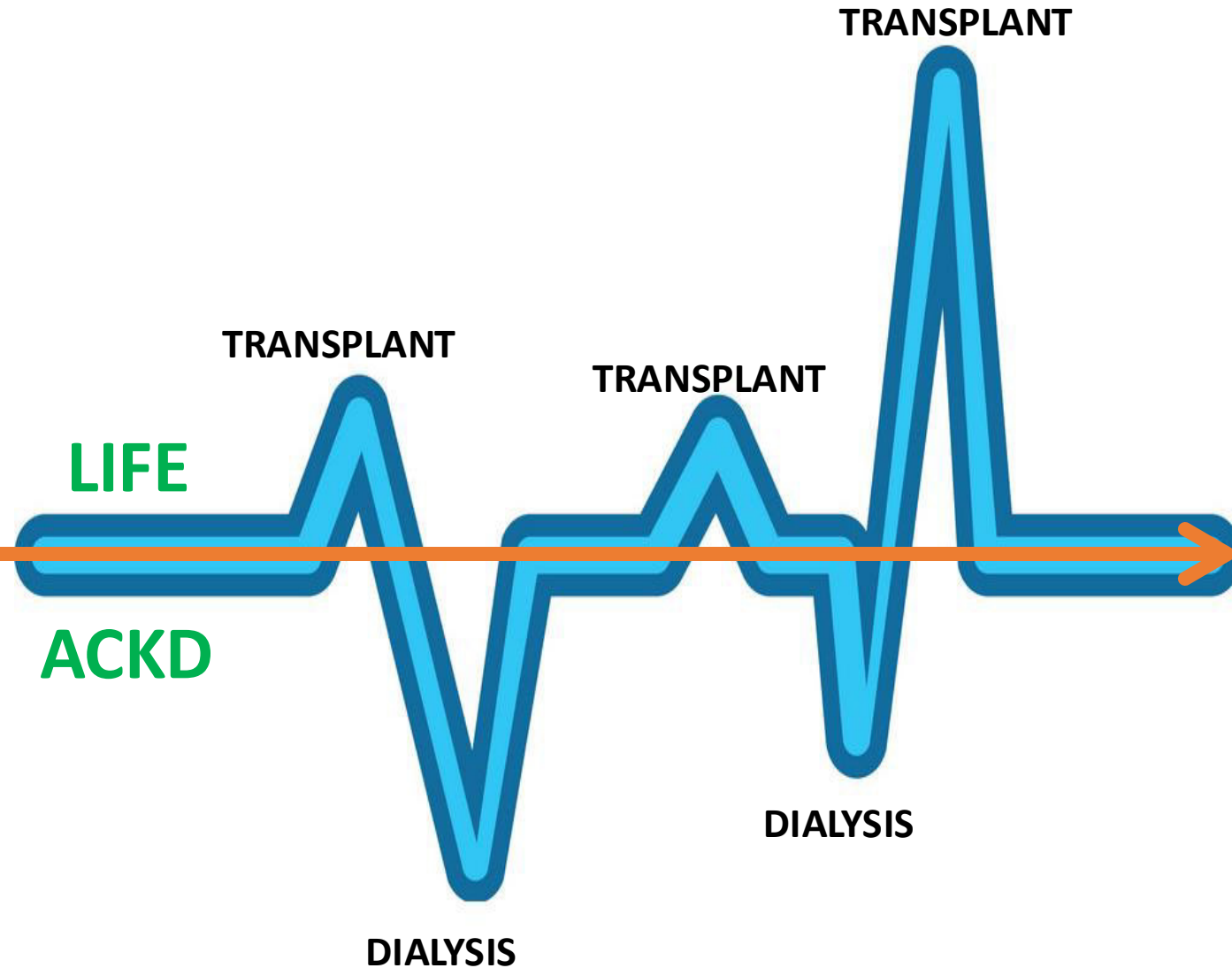


Daniel Gallego  
EKPF president



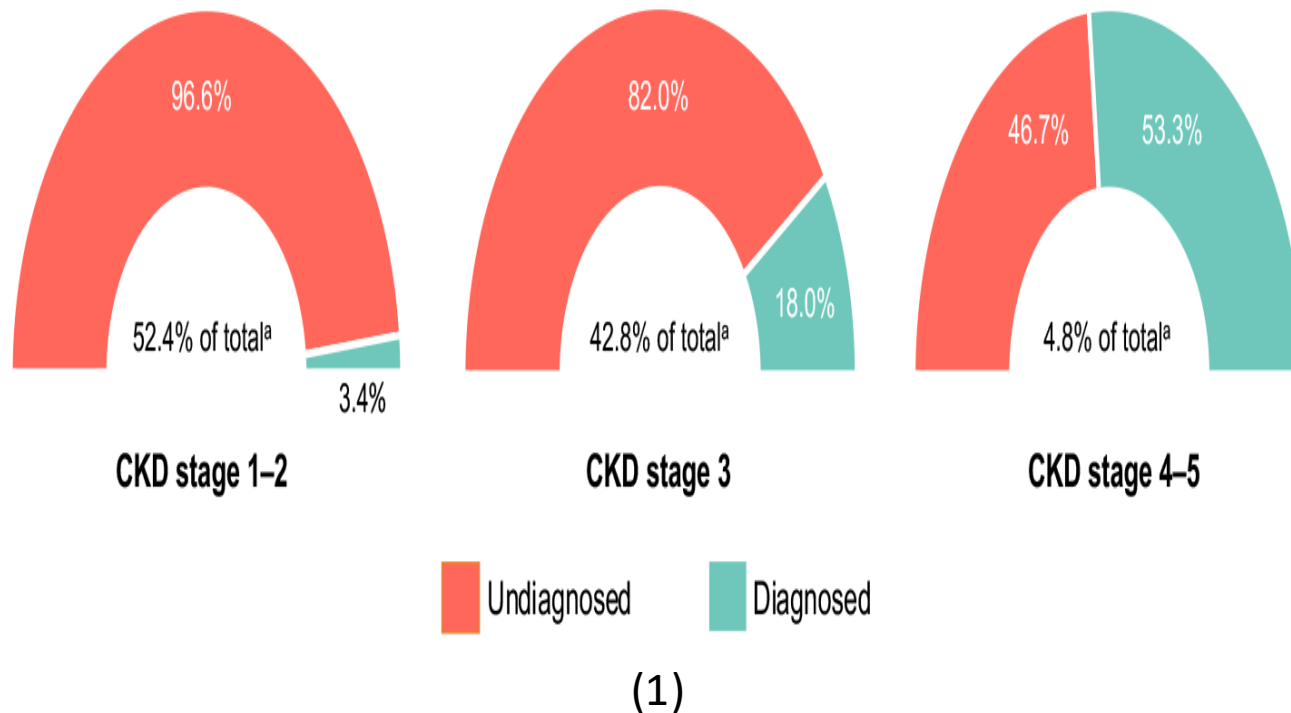
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# KIDNEY PATIENT JOURNEY



- Candidates To 2 Or More Tx
- Only 15% Candidates Tx
- 85% REMAINS IN HD 4EVER
- TX Graft Rejection
- TX Duration 12/15 Years Avg.
- Dialysis Not Replace Kidneys (Only Small Fraction)**
- PREVENTION & EARLY DETECTION**

# ELEVATE CKD PUBLIC HEALTH PRIORITY



- Prevention & Early Diagnosis**
- All available KRT are Far from Adequate
- No Health Policy is complete without Prevention and Early Detection
- Delayed Diagnosis = Reduced LifeSpan
- No Prevention = Compromised QoL
- CVD Major Cause Death undiagnosed CKD
- Effective Strategies High Risk Groups
- Patient Organizations Advocacy**

(1) World Economic Forum, Health & Healthcare Systems, Early Detection of CKD can save lives and cut costs

# POLICY RECOMENDATIONS EARLY DETECTION

## Factors affecting Chronic Kidney Disease (CKD)

(1)



Diabetes



Age



High Blood  
Pressure



Smoking



Heart Problem  
or Stroke



Obesity



Family  
History

- Awareness & Education
- Expand Screening Programs
- Strengthen Primary Care Structure
- Promote Digital Solutions
- Incentivize Preventive Measures
- Enhance Data Collection & Research
- Address Health Inequalities
- Best Practices Sharing EU
- Foster Collaboration

(1) Samrat Kumar Dey, Khandaker Mohammad Mohi Uddin, Hafiz Md. Hasan Babu, Md. Mahbubur Rahman, Arpita Howlader, K.M. Aslam Uddin, Chi2-MI: A hybrid feature selection based machine learning approach in diagnosis of chronic kidney disease, Intelligent Systems with Applications, Volume 16,2022, 200144, ISSN 2667-3053, <https://doi.org/10.1016/j.iswa.2022.200144>.



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# Q&A Session



**Acknowledgement of support:** The European Kidney Forum is made possible through the financial support of industry partners, including Astellas, AstraZeneca, Bayer, Baxter, B. Braun, CSL Behring, Fresenius Medical Care, GSK, Hansa Biopharma, Mozarc, Novartis, Novo Nordisk, Sobi, and Vifor Pharma.





# Closing Remarks



**MEP András Kulja**  
(EPP, Hungary)



**Prof. Raymond Vanholder**  
EKHA President



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- **Burden**
  - **Cost**
  - **Mortality (silent killer)**
  - **Environment**
- **Prevention**
  - **Lifestyle + Blood pressure and glycemia**
  - **Medication**
  - **Environment**
  - **Transplantation**
  - **Screening**
    - **Albuminuria**
  - **Education**
    - **Kidney Health**
    - **Albuminuria**

# **ASKS**

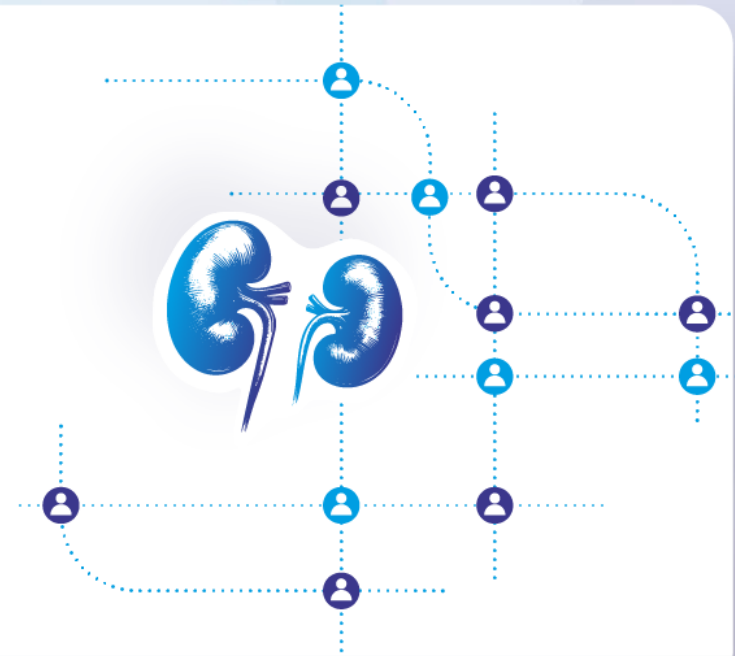
- **More awareness**
- **More screening**
- **More funding**
  - **Innovation**



# Networking Reception

18:00-19:15

12<sup>th</sup> Floor Restaurant, EP Spaak Building



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# VR

EXPERIENCE SESSIONS



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# Thank you!

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