

2026 International GeGe4Nephro Symposium

Patients' perspective on importance of sex-specific research

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The European Rare Kidney Disease Reference Network
für Patienten

BUNDESVERBAND NIERE E.V.

About me

- Senior IT Security Engineer and Senior Project Manager (Retired)

- **Board member of:**
  - PKD International;
  - Bundesverband Niere e.V.
  - Former Co-Chair, ERKNet ePAG;
- **Contributor to:**
  - international clinical practice guidelines and research initiatives





DIAGNOSIS ADPKD AT THE AGE OF 25

– AND NOW?

25 Shock Diagnosis
Gradual loss of kidney function and comorbidities
48 – Start of Dialysis
Severe limitations – quality of life
50 – Kidney Transplantation
Through living donation from wife
Today - Risks
, …





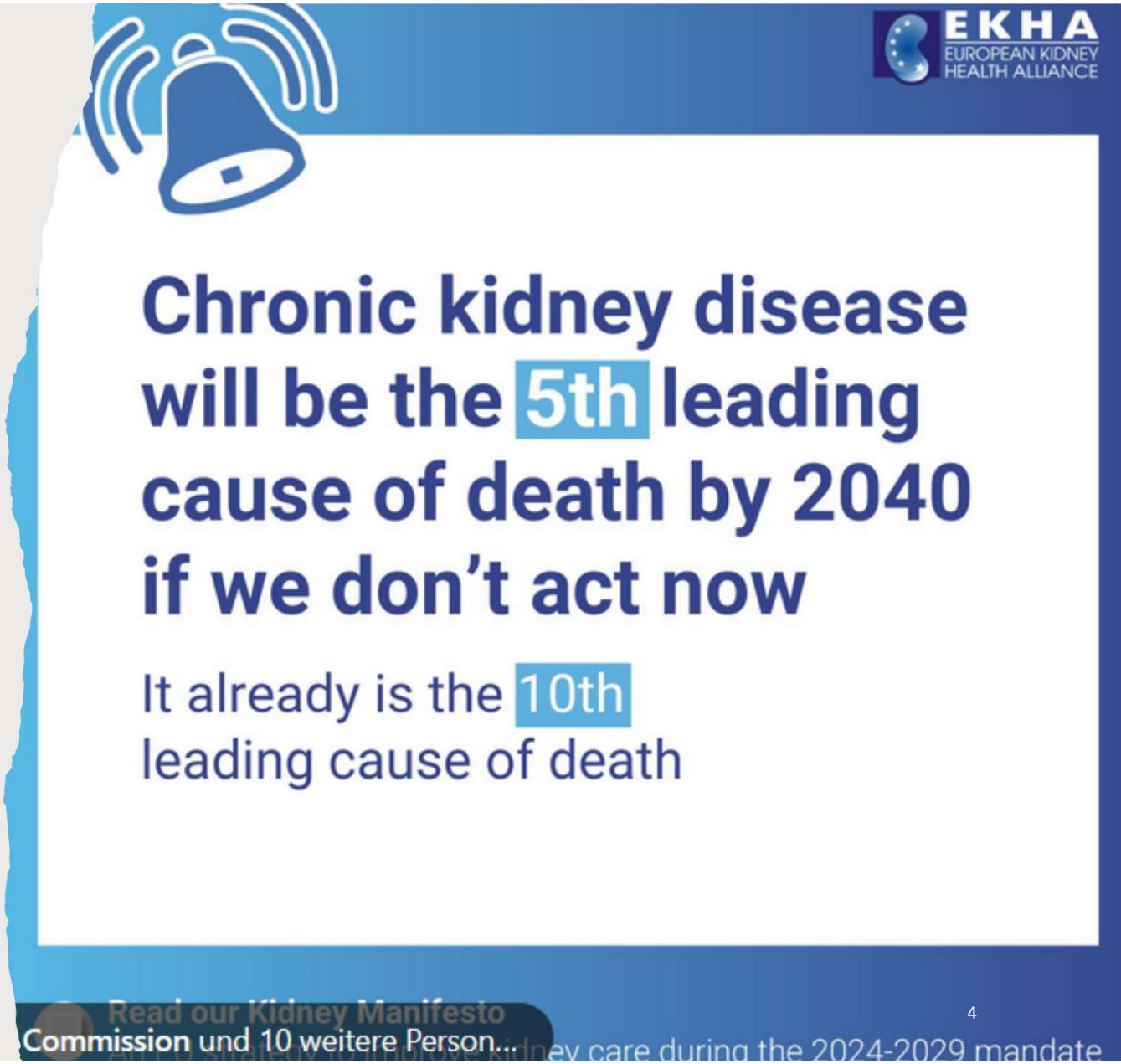
"The diagnosis hit me like a shock: a shortened life expectancy, being advised against having children, and the prospect of early dialysis. Even today, there is a lack of effective treatments and adequate care for people with rare diseases. Urgent improvements in healthcare are essential."

Sex, Gender and Global Inequalities in CKD (Overview)

Key Messages

- CKD affects **more than 850 million people worldwide**.
- It is among the **leading causes of death** globally and continues to rise.
- **Sex, gender, geography, income and ethnicity all influence kidney health.**
- Improving outcomes requires **equitable access** to prevention, diagnosis and treatment.

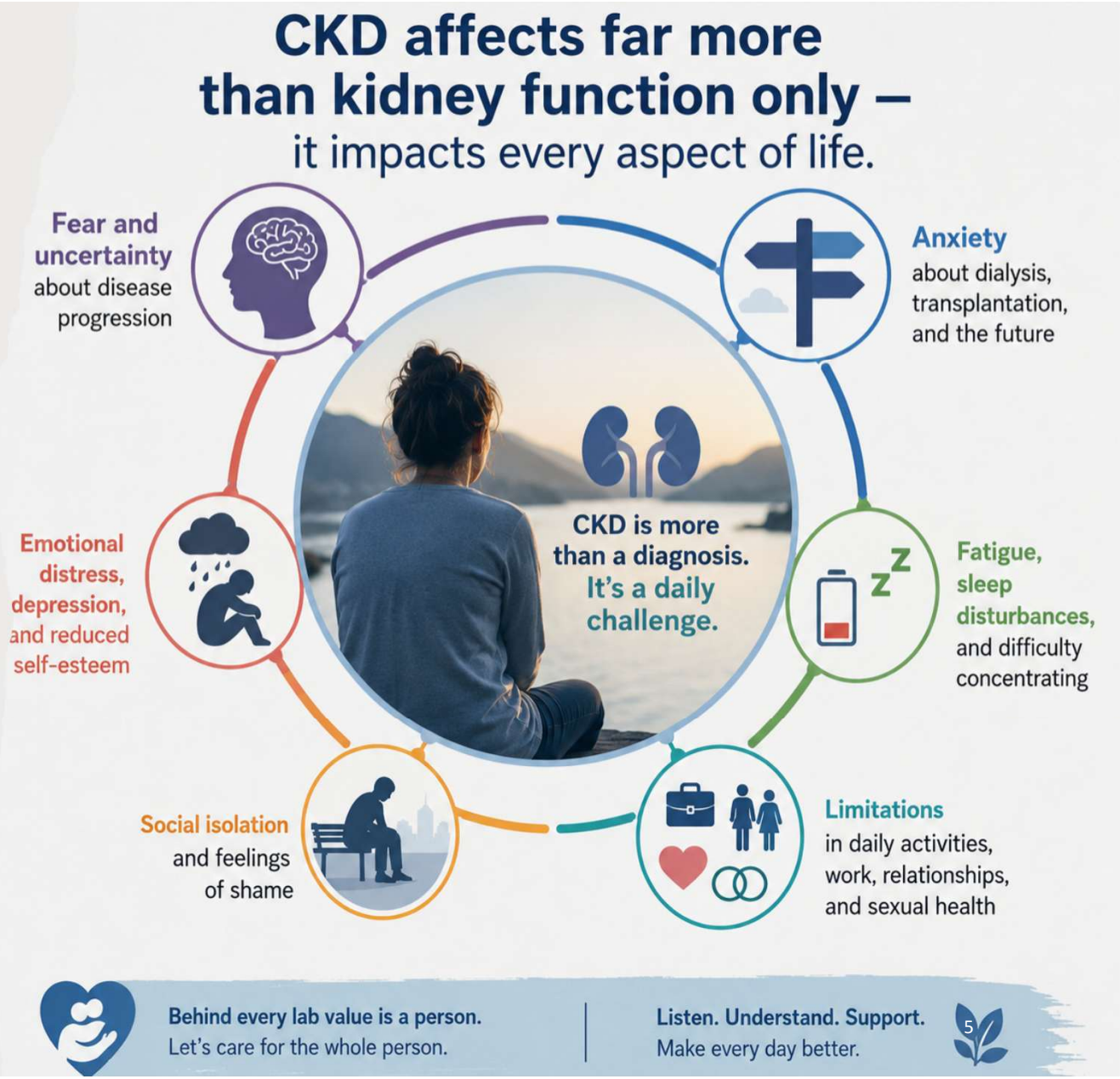
Source: Global Burden of Disease; ISN Global Kidney Health Atlas;



Living with Chronic Kidney Disease – The Patient Perspective

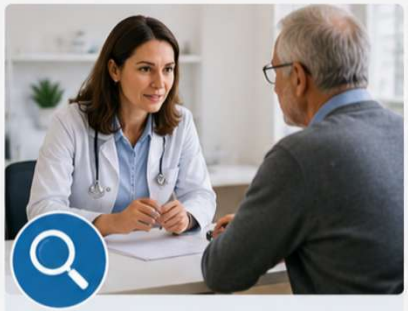
Key message:

- **Patients experience CKD as :**
  - **lifelong physical,**
  - **emotional, and**
  - **social burden—**
- **not just a medical condition.**
- **Gender differences !!**



What People with CKD Need to Live Well

Beyond Treatment – Toward a Better Quality of Life



Early diagnosis and timely intervention

Detect CKD early and act promptly to slow progression and prevent complications.



Shared decision-making and personalized treatment

Work together with your healthcare team to choose the best options for your values, goals, and life.



Better symptom manage especially fatigue and mental health

Address fatigue, sleep probl pain, and emotional well-bei as part of comprehensive ca



Access to psychological and peer support

No one should face CKD alone. Support groups, counseling, and peer connections make a real difference.



Maintaining independence, employment, and family life

Support the ability to work, stay active, and enjoy meaningful relationships and daily life.



Research that improves quality of life— not only kidney functior

Invest in research that focuses symptoms, daily life, and what matters most to patients.

Better care. Better support. Better life.

Because every person with CKD deserves to live well.

9:29:13 AM

Key message:

For patients, success is measured not only by slowing CKD progression, but:

- **preserving quality of life,**
- **dignity, and**
- **participation in everyday life.**

- **Gender differences!**

In the care reality for people with chronic kidney disease (CKD) there are substantial sex-specific differences



Men

- **Higher risk** of CKD progression and cardiovascular complications
- **Faster decline** of kidney function
- **Higher likelihood** of reaching kidney replacement therapy
- **Higher** CKD-related mortality





Women

- **Higher prevalence** of CKD
- **Later diagnosis** and under-treatment
- **Lower referral** to nephrology and less guideline-adherent care
- **Lower** CKD-related mortality than men (when adjusted)

Women and Men Experience CKD Differently

- Women have a higher prevalence of CKD.
- Men lose kidney function faster.
- Men develop albuminuria more frequently.
- Men are **30–70% more likely** to progress to kidney failure.
-
- Biological differences (sex hormones, immune response, kidney physiology) contribute to these disparities.
- Estrogen appears protective before menopause;
- testosterone may promote kidney injury.

Sex Differences in CKD Care Continuum – Germany

Versorgungsschritt	Frauen	Männer	Kernaussage	Primäre Quelle
CKD (G1–G5)	ca. 13–14 %*	ca. 11–12 %*	Frauen häufiger betroffen	DEGS1 / Girndt et al. 2016; internationale Einordnung durch CKD Prognosis Consortium Eurotransplant c...
eGFR <60 ml/min (G3a–G5)	4,6 %	3,0 %	Frauen häufiger reduzierte eGFR	Trocchi et al., BMC Nephrology 2017
Albuminurie ≥30 mg/L	9,6 %	13,4 %	Männer häufiger Albuminurie	Girndt et al., DEGS1
Dialysepatienten (Prävalenz)	ca. 38 %	ca. 62 %	Männer deutlich häufiger in Dialyse	QuaSi-Niere Jahresbericht
Nierentransplantationen (Empfänger)	ca. 38–40 %	ca. 60–62 %	Männer erhalten häufiger eine Niere	Eurotransplant Deutschland Eurotransplant c... +1

1. Diagnosis and Medical Treatment

- Women are often diagnosed later because lower serum creatinine can mask CKD.
- Drug metabolism and pharmacokinetics differ between women and men.
- Women remain **underrepresented in nephrology clinical trials**.

Key message:

- More sex-specific evidence is needed for drug efficacy and safety.
- Personalized treatment should consider biological sex.

2. Dialysis in Germany – Sex differences

Around **100,000 patients** receive kidney replacement therapy (dialysis or transplantation) in Germany.

61.6% of dialysis patients are **men**

38.4% are **women**

Men are **~60% more likely** to require dialysis than women

This reflects the **faster progression of CKD in men**, despite CKD being more prevalent in women

Similar male predominance is observed internationally (DOPPS: **59% men vs. 41% women**)

Key message:

Dialysis prescriptions should consider body composition and individual needs.

3. Kidney transplantation in Germany – sex differences

- Data from German transplant registry analyses (2006–2020):
  - **63% of kidney transplant recipients were men**
  - **37% were women**
- Men therefore represent approximately **two-thirds of kidney transplant recipients**.
- This reflects the higher proportion of men progressing to kidney failure requiring kidney replacement therapy.
- In contrast, women represent the majority of living kidney donors.

Key message:
Access to transplantation should be equitable regardless of sex.

Patient Perspective on sex-specific research needs



Research and Future Directions

- Sex and gender should be included in all kidney research.
- Clinical trials should recruit equal numbers of women and men.
- CKD registries should routinely analyze outcomes by sex.
- Develop sex-specific clinical guidelines where appropriate.

Individualized medicine with KI-Tools enables earlier, targeted CKD prevention and treatment

TODAY

AI already works

Early detection
Risk stratification
Progression prediction

2026–2030

CLINICAL INTEGRATION

External validation
EHR decision support
Regulation & workflow

~2030+

PRECISION NEPHROLOGY

Multimodal data + omics
Personalized treatment
Adaptive monitoring



~2030: AI-enabled precision nephrology

Earlier detection • better risk prediction • more individualized CKD treatment

Prerequisite: National and European CKD registries are needed to provide high-quality data for better AI.

Important: 2030 is a plausible transition horizon—not an official implementation deadline. Broad adoption depends on prospective validation, regulation, interoperability, clinician oversight and trust.

Sources: Cheungpasitporn et al., Clin Kidney J 2026; Yuan et al., Int Urol Nephrol 2026; Tangri & Sabanayagam, Nat Rev Nephrol 2025; ASN AI Workgroup, JASN 2026.

We need big data / registries for research and KI-research

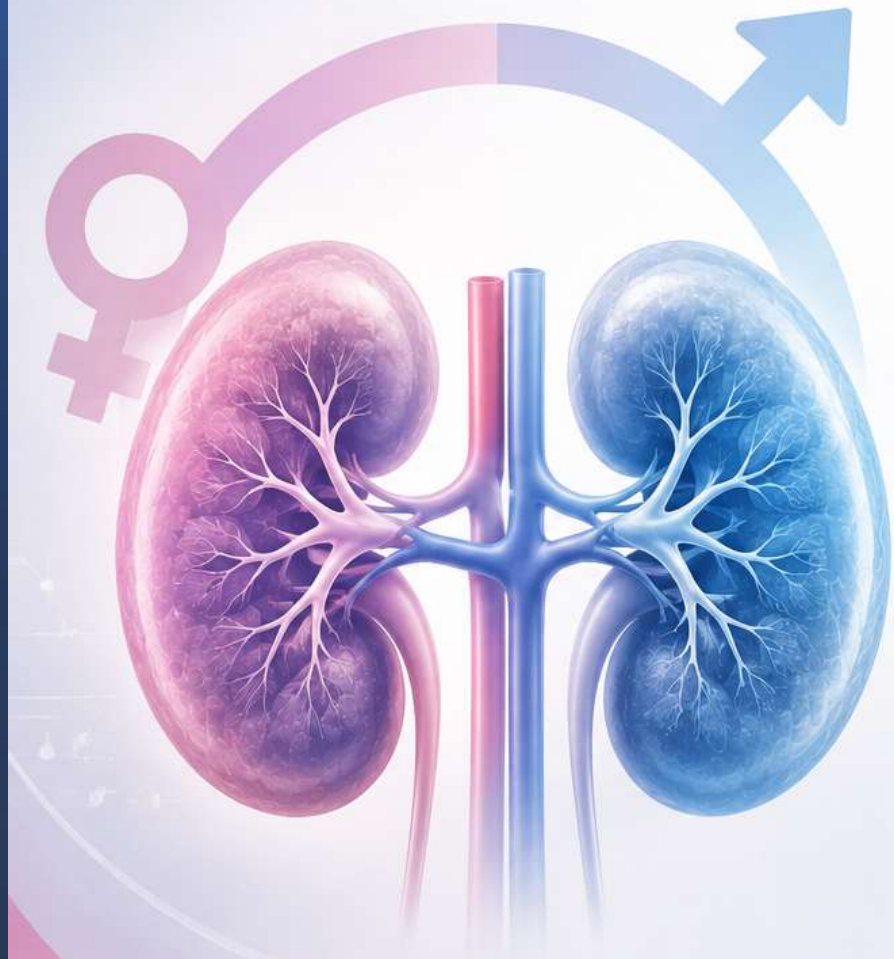
national and EU-wide

Need for nationwide (european) registries

- Establish a nationwide, continuously updated CKD registry to enhance early detection, optimize patient care, improve clinical outcomes, and support research.
  Facilitate data sharing and interoperability across Europe.

Benefits

- Provide reliable prevalence, incidence, and longitudinal data across all stages of CKD.
- Enable transparent quality assurance and benchmarking across outpatient and hospital care.
- Support early, targeted interventions for high-risk populations and people living with rare kidney diseases.
- Provide a robust evidence base for health policy, healthcare planning, resource allocation, and prevention strategies.
- Strengthen research infrastructure through real-world data, secure data linkage, and registry-based randomized clinical trials (RRCTs).



Thank You!

Patients' perspective on the importance of sex-specific research

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Better research.