REPORT

ACTIVITY

EUROPEAN KIDNEY PATIENTS FEDERATION

OCTOBER 2025



EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR

Uniting for Kidney Health:
Empowering Lives, Enhancing Futures









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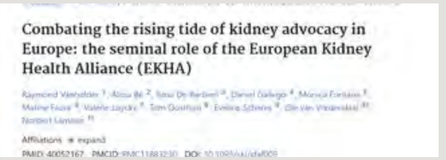
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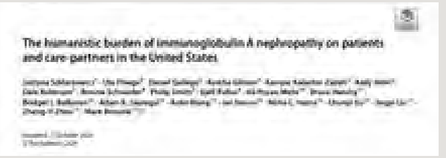
PUBLICATIONS

PUBLICATIONS

TITTLE	DATE
Combating the rising tide of kidney advocacy in Europe: the seminal role of the European Kidney Health Alliance (EKHA)	January, 2025
Kidney Disease: Improving Global Outcomes (KDIGO) Workshop on the Nurse’s Role in Managing the Symptoms of People Receiving Dialysis	February, 2025
The humanistic burden of immunoglobulin A nephropathy on patients and care-partners in the United States	April, 2025
Can We Lower the Burden of Antimicrobial Resistance (AMR) in Heavily Immunocompromised Patients? A Narrative Review and Call to Action	May, 2025


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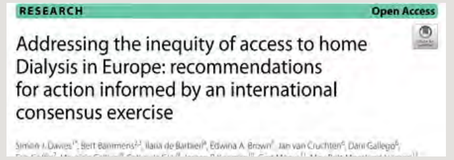
PUBLICATIONS

TITTLE	DATE
ABCDE to identify and prevent chronic kidney disease: a call to action	June, 2025
2023 European Kidney Forum: The future of kidney care – investing in green nephrology to meet the European Green Deal targets	June, 2025
A call for urgent action on chronic kidney disease across Europe	June, 2025
Addressing the inequity of access to home Dialysis in Europe: recommendations for action informed by an international consensus exercise	June, 2025





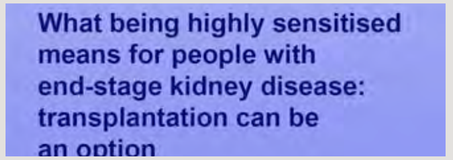




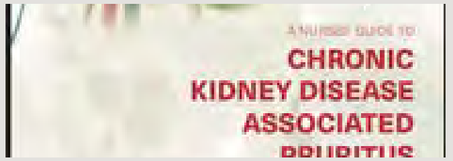
PUBLICATIONS

TITTLE	DATE UPLOADED
The ESOT–Lancet Commission on Transplantation: a new vision for global sustainability, innovation, and equity in organ transplantation	July, 2025
What being highly sensitised means for people with end-stage kidney disease	October, 2025
Use of surrogate endpoints in health technology assessment and reimbursement of treatments for the management of chronic kidney disease	October, 2025
A nurse’s guide to Chronic Kidney Disease Associated Pruritus	October, 2025










Welcome to IgAN Friends,
your new support website
for patients, from patients
IgAN Friends is a supportive
community of people living with
IgA Nephropathy
Scan the
QR code
to visit
www.igaNfriends.org
UNITING FOR
KIDNEY HEALTH:
PROJECTS
geneTIGA
Gene-edited T cells
combating IgA
Nephropathy
www.genetiga-horizon.eu
PREVENTCKD
Shifting gear in CKD
prevention
www.kidneyhealthcode.eu
KitNewCare
Sustainable Care, Lasting Impact

EU PROJECTS

2025 EU PROJECTS



geneTIGA

Horizon Europe

European Commission

EU4health

PREVENTCKD

EU4HEALTH



KITNEWCARE

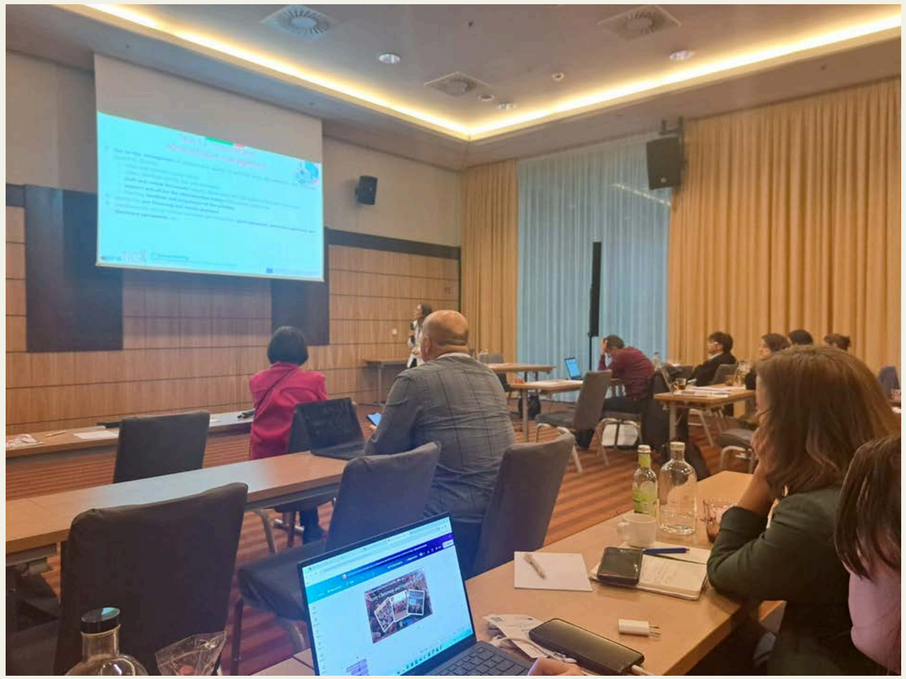
Horizon Europe

geneTIGA



- 2022-2026
- Annual meetings
- Our role is in communication and dissemination of project results

The ultimate goal of the project is to develop a safe and efficient cell therapy based on genomically edited T cells with redirected specificity to sustainably combat IgA nephropathy (IgAN), the most common glomerulonephritis and one of the most frequent causes of end-stage renal disease with unmet medical needs.

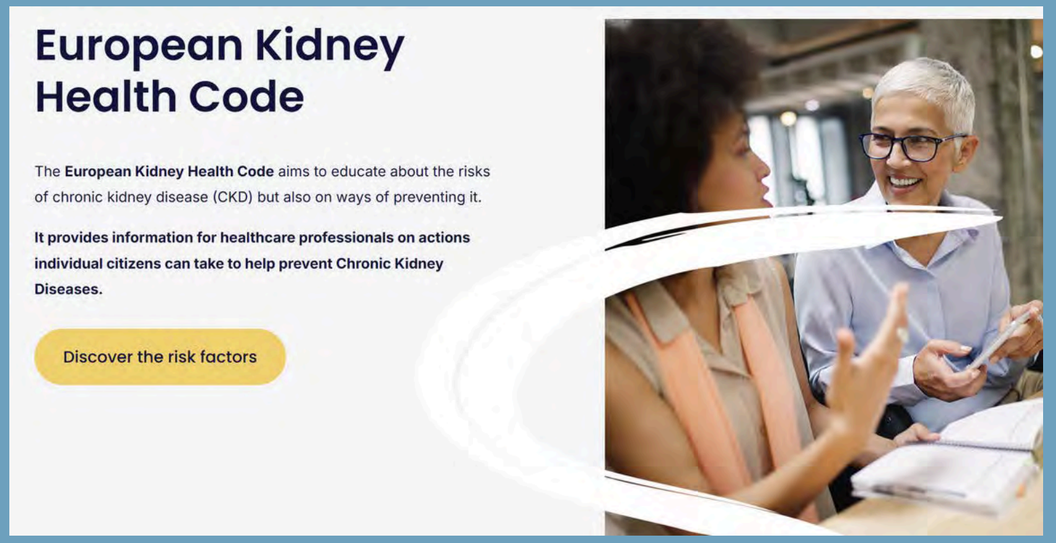


ENHANCEMENT OF PREVENTION OF CHRONIC KIDNEY DISEASE IN THE EU: A TARGETED APPROACH TO TAKING ACTION

PREVENTCKD

- *2023-2025*
- *In charge of Quality plan and Best practices analysis*
- *Important role in dissemination and communication*

Increase awareness on the characteristics, implications and impact of CKD at EU population level and EU policy level, Preventing CKD from developing; Screening population at risk; Stimulate health-management for people with kidney disease prior to the stage necessitating kidney replacement therapy, to enhance quality of life, mental health and delay the process of deterioration of the kidney function and to minimize societal cost



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 styles, 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)

KitNewCare

Sustainable Care, Lasting Impact



- 2023-2027
- Annual meetings
- In charge of the Patient and Public Involvement Program
- Our role is in communication and dissemination of project results

KitNewCare is working on a sustainable healthcare model, focusing on kidney care due to its significant impact. The project involves mapping sustainability, developing workflows, piloting innovations, and creating guidelines. It aims to inform decision-makers and establish a Sustainability Network for long-term impact beyond EU funding, with stakeholder involvement throughout the process.

COLLABORATION WITH EU PROJECTS

PROTECT-CHILD

A Privacy-Protecting Environment for Child Transplants health-related and genomic data integration in the European Reference Network

TTVguideTX

Torque Teno Virus Based mmune Monitoring. Establishing a tool to guide immunosuppression



RENAL LIFECYCLE

Investigating the protection of heart and kidneys in patients with severe kidneyfailure

PERSONALISE-DKD

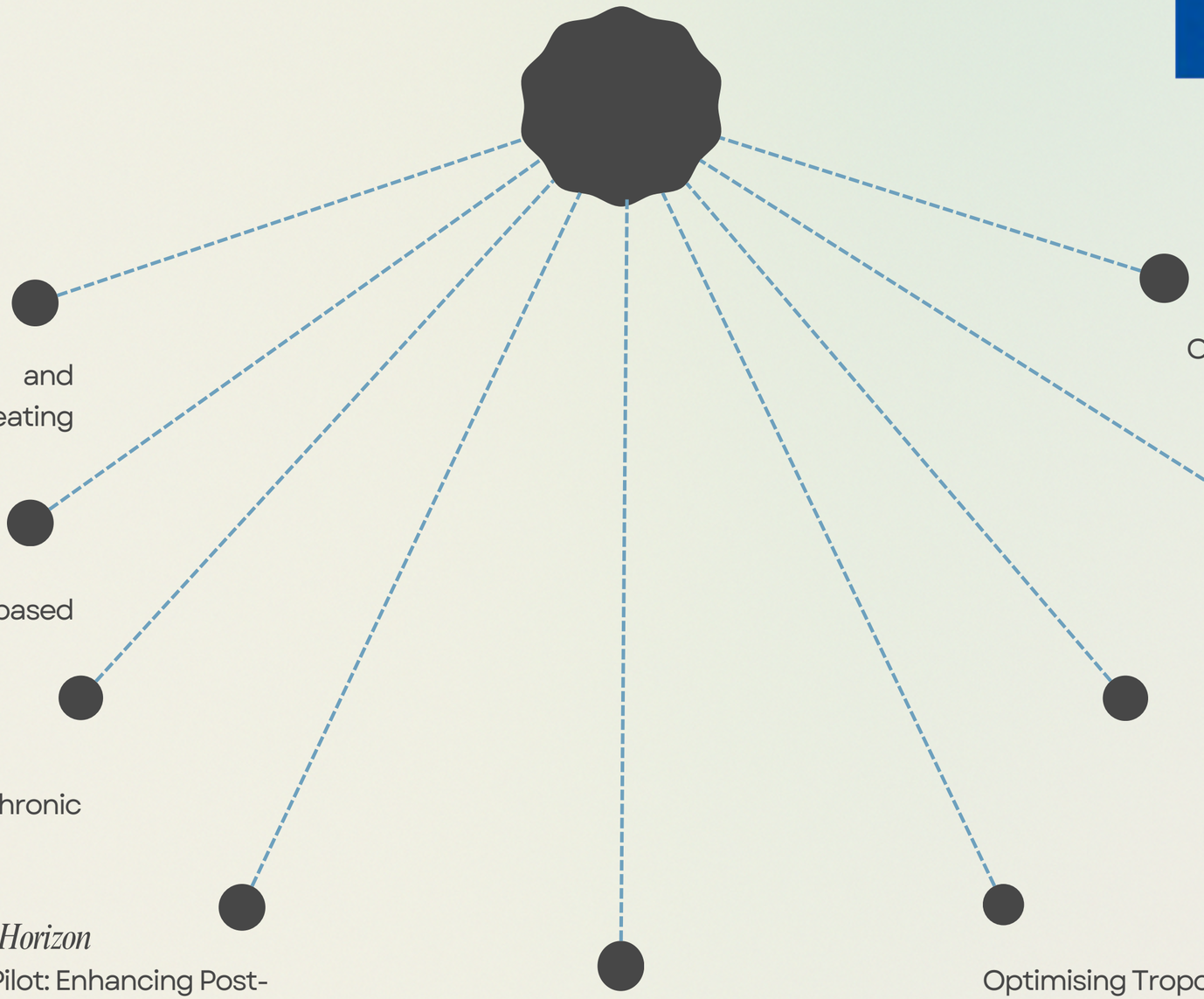
Personalised SGLT2i treatment in diabetic kidney disease supported by multiparametric renal magnetic resonance imaging

CORDIAL

Validates WEAKID, a portable peritoneal dialysis system that regenerates dialysate to improve clearance and protect the membrane

EU CALLS

Funded by the European Union



ALP-RARE - Erdera

A pre-clinical target validation and therapy studies pipeline for treating human Alport spectrum disease

REPAIR-CKD - Horizon

Advancing cell secretome-based therapies

MOMENTUM - Horizon

Mild Cognitive Impairment in Chronic Kidney Disease (MCI-CKD)

PROM-AI-THEUS - Horizon

Kidney Transplant Pilot: Enhancing Post-Transplant Care through a Multimodal Generative AI Assistant

P-PEAKS - Horizon

Innovative phage therapy to combat antibiotic-resistant urinary tract infections.

ADAPT-UP - Horizon

Optimising Troponin Interpretation and Use AMong Individuals with Reduced Kidney Function

KAI-BRIDGE - Horizon

Kidney AI for Better Research, Implementation, Decisions, Guidelines, and Equity

ELASTIK - Horizon

Kidney AI for Better Research, Implementation, Decisions, Guidelines, and Equity

AlloTreat - Horizon

Off-the-shelf Allogeneic T Regulatory cells for Adoptive Therapy to sustainably rebalance the inmune system



COLLABORATORS


EKHA
EUROPEAN KIDNEY
HEALTH ALLIANCE


World Health
Organization


EDTNA/ERCA
Caring Together


European
Commission


ESOT


AFFILIATED
ORGANISATION
of
IKCC
International
Kidney Cancer
Coalition


AAKP
American Association of Kidney Patients
aakp.org


GLOBAL PATIENT ALLIANCE for
KIDNEY HEALTH


ERA
LEADING EUROPEAN NEPHROLOGY


62nd ERA CONGRESS
VIENNA & VIRTUAL
JUNE 4-7, 2025
Beyond Nephrology
in collaboration with
Österreichische Gesellschaft für Nephrologie
Vienna
ERA
LEADING EUROPEAN NEPHROLOGY

MEETINGS





EUROPEAN KIDNEY FORUM 2025

Brussels, January 28th

KITNEWCARE GENERAL ASSEMBLY

Madrid, March 11th and 12th

GLOBAL KIDNEY CANCER SUMMIT

Madrid, 4th-6th April



GLOPAKH'S STEERING COMMITTEE

Boston, 8th - 9th April







ERKNET'S EUROPEAN MEETING

Belgium, 20th April

ERA CONGRESS 2025

Vienna, 4-7th June

PERSONALISE-DKD EP-PERMED PROJECT MEETING

11th June, Bergamo



GLOBAL PATIENT PARTNERSHIP SUMMIT

9-11th June, Barcelona



EKHA GENERAL ASSEMBLY

23rd June, Brussels





EKHA MEETING WITH MEP GROUP FOR KIDNEY HEALTH

24th June, Brussels



EUROPD INTERNATIONAL CONFERENCE 2025

8th-20th October, Valencia

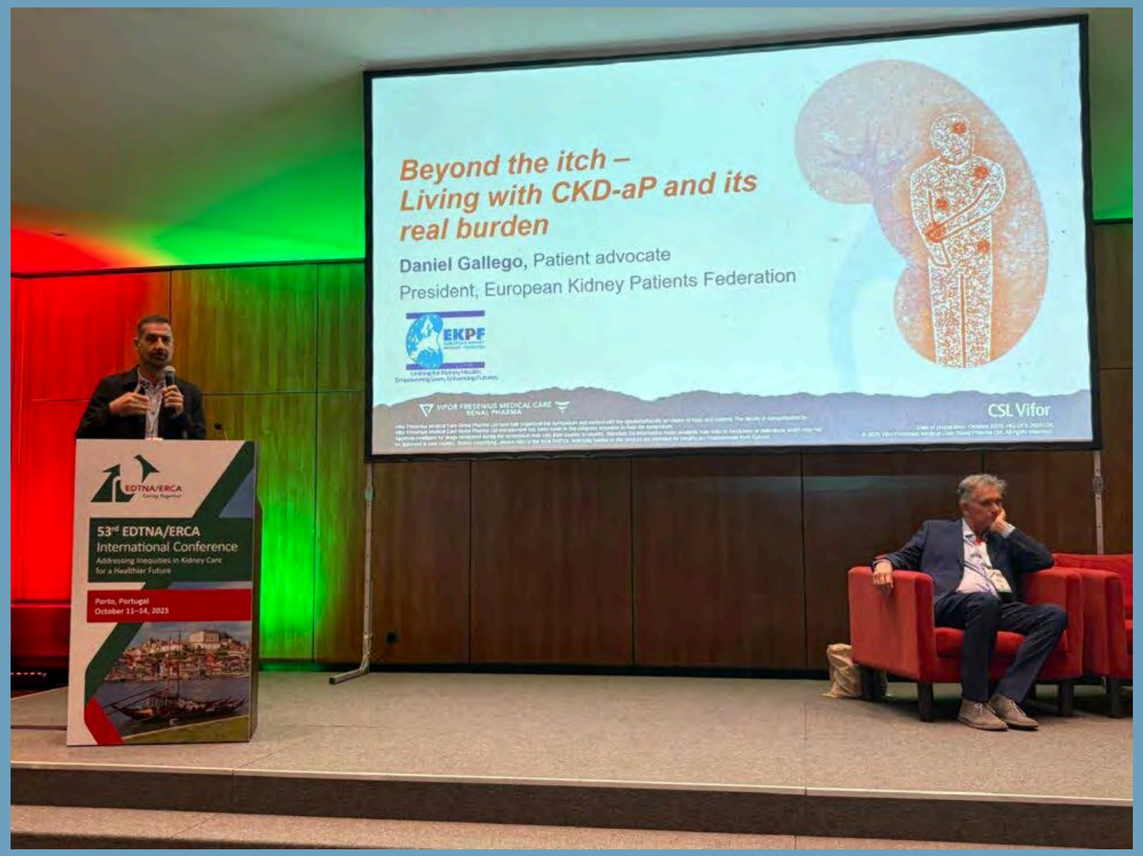


ESOT CONGRESS 2025

29th June-2nd July, London

EDTNA/ERCA INTERNATIONAL CONFERENCE

11-14th October, Porto



6TH INTERNATIONAL RENAL MRI MEETING

13-14th October, Pamplona




Garderobe
Garderobe
EKPF
2024
Berlin, Germany
SUMMIT
Berlin, 17th October, 2024

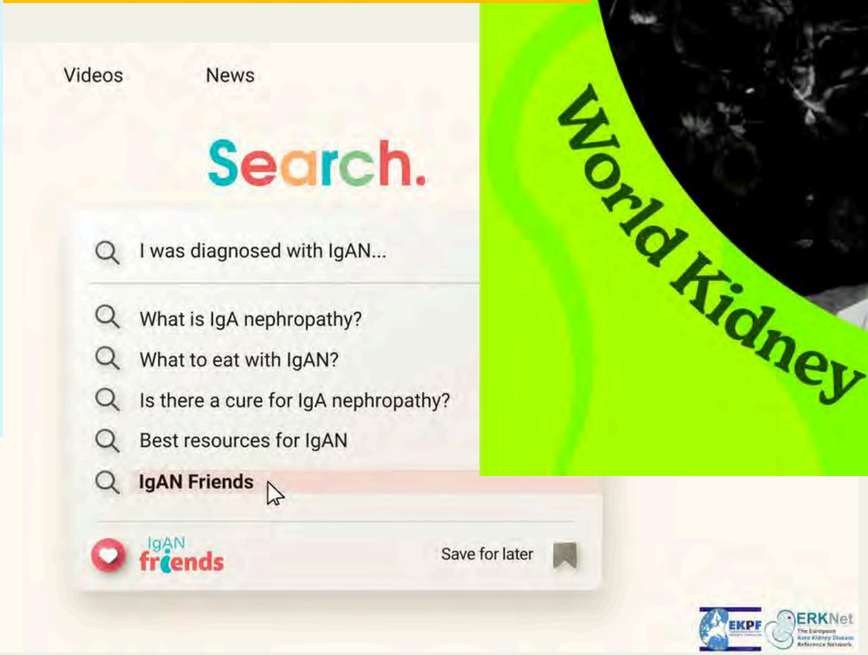
AWARENESS


RARE DISEASE DAY
February 28th
"More than you can imagine"


ACCESS TO HEALTHCARE
SAVES LIVES.
Pregnancy can be a dangerous time in a woman's life.
World Health Organization


Show your kidneys some love
World Kidney Cancer Day | 19 June 2025


Today is
World Kidney Day
13 March 2025


Videos
News
Search.
I was diagnosed with IgAN...
What is IgA nephropathy?
What to eat with IgAN?
Is there a cure for IgA nephropathy?
Best resources for IgAN
IgAN Friends
IgAN friends
Save for later
EKPF
ERKNet

WEBINAR

TTV-Guided Immunosuppression

Exploring the Role of the **Torque Teno Virus (TTV)** as a Biomarker for Personalized Immunosuppressive Drug Therapy in Kidney Transplant Recipients

Speaker: Frederik Haupenthal, MD, Medical University Vienna

February, 18th
2pm CET

Ethical Dimensions in Clinical Trial

Informed Consent, Therapeutic Misconception, and Ethical Challenges in Research

Speakers: Alberto Molina Perez, Gonzalo Díaz Cobacho, University of Granada

February, 20 th
2pm CET

REGISTER NOW!

Organized by TTVguideTX & EKPF

EKPF EUROPEAN KIDNEY PATIENTS FEDERATION
Uniting for Kidney Health: Empowering Lives, Enhancing Futures

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RareConversations
Collective action for rare diseases

This meeting is organised and funded by Alexion, AstraZeneca Rare Disease

YOU ARE INVITED

Please join RareConversations, a global forum on today's rare disease challenges

Advancing Rare Disease Healthcare:
Spotlighting the Economic and Health System Burden of Disease

Live sessions on Tuesday 23 September 2025 at two different times:

Session 1: 07:00 EDT | 13:00 CEST | 15:00 GST

Session 2: 11:30 EDT | 17:30 CEST | 19:30 GST

Upcoming webinar

'Transplant Patient Journey Around Infectious Diseases'

April 24th, 2025

17:30 - 18:30 CEST

ESOT

WEBINAR

La participación de los pacientes en la defensa nacional de la salud renal y la implementación de la Resolución de la OMS:
es el momento de actuar



MIÉRCOLES 8 DE OCTUBRE
10:00-10:30 h CDT / 17:00-17:30 h CET

REGÍSTRATE AHORA

GLOBAL PATIENT ALLIANCE for KIDNEY HEALTH

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reminder

COFFEE & CHAT

APRIL 29TH 3PM CEST

WITH IgAN friends

IgANfriends.org



EKPF ERKNet

ISN | ACADEMY

WEBINAR

World Kidney Day 13 MARCH 2025

March 4 | 1 p.m. CET

ARE YOUR KIDNEYS OK?
Detect early, protect kidney health

World Kidney Day 2025 Webinar
Are Your Kidneys OK?
Detect Early, Protect Kidney Health

MODERATOR

Augusto Cesar Soares Dos Santos
Brazil

SPEAKERS

Anna Francis
Australia

Joseph Vassalotti
USA

Claudia D'Alessandro
Italy

Rajalakshmi Ravi
India

Live subtitles available in over 50 languages



KREW CAMP











EKPF CAMPUS

APIR
Associação Portuguesa de
Insuficientes Renais



OVERVIEW

KREW CAMP 2025 took place from 6th to 12th July in Obidos, for teenagers aged 12 to 16 with kidney disease. The camp was organized by EKPF in collaboration with APIR (Portuguese Association)

Participation:

- Netherlands: 5 teenagers + 1 nurse + 1 representative
- Finland: 3 teenagers + 1 nurse + 1 representative
- Poland: 5 teenagers + 1 nurse + 1 nephrologist
- Portugal: 5 teenagers + 1 nurse + 3 representatives
- Spain: 5 teenagers + 1 nurse + 1 representative





ACTIVITIES

- Medieval Town of Obidos
- Trip to Nazaré and Hippotrip tour
- Nutrition Workshop
- Themed national nights
- Canoeing, zipline, paintball, climbing











KREW CAMP

July, 2025

Obidos,
Portugal



IGAN FRIENDS

IGAN FRIENDS



IgAN Friends is a **Pan-European community connecting and empowering people living with IgA Nephropathy** (IgAN).
Created by the EKPF, it aims to build solidarity, share experiences, and amplify the patient voice across Europe.

Highlights 2025

- Community launch and refreshed website in 5 languages.
- Over 30 members joined so far.
- First Coffee & Chat session and Newsletter launched.
- Participation in the ERA Congress 2025 (Vienna).
- Introduction of a Welcome Pack for new members.



SOCIAL MEDIA

LINKEDIN

EKPF - European Kidney Patients' Federation
805 seguidores
3 meses •

KREW Camp 2025 – Final Days Recap

Day 5: A day in Lisbon! Campers explored the city, enjoyed packed lunches, ... más

Mostrar traducción



Antonio Cabrera Cantero y 18 personas más 3 veces compartido

FACEBOOK

European Kidney Patients' Federation
13 de junio ·

Proud moment! 🎉

Last week at the European Renal Association 2025 Congress in Vienna, our colleagues Mónica and Juan Carlos represented EKPF and the patient voice in three major European projects: geneTIGA, KitNewCare, and PreventCKD.

Our dedication in these projects ensures that patient perspectives remain at the heart of innovation in kidney care and research across Europe👏

Read more about our projects here: https://ekpf.eu/

#ERA2025 #kidneyresearch #kidneycare



EKPF

geneTIGA

PREVENTCKD

KitNewCare
Sustainable Care, Lasting Impact

TWITTER (X)

EKPF
@EKPFpatients

📢 New study alert!

IgA Nephropathy (IgAN) deeply impacts patients & care-partners—mentally, physically, and professionally.

🧠 49% of patients reported moderate/ severe depression

📉 Work productivity losses over 30%

📖 Co-authored by EKPF President Daniel Gallego.
#IgAN



INSTAGRAM



Uniting for Kidney Health: Empowering Lives, Enhancing Futures

EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION

NEWSLETTER

JUNE 2025

www.ekpf.eu



Have You Experienced Itching During Dialysis? Help Shape Future Care!



EKPF Brings the Patient Voice to ERA 2025 Congres

e EKPF was proud to attend the ERA 2025 Congress in Vienna, representing kidney patie
m across Europe. During those days, we welcomed visitors at our booth, sharing our w
ojects, and advocacy initiatives.

part of our involvement, EKPF President Daniel Gallego took part as a speaker in one of
st thought-provoking sessions of the event: "Pro & Cons: Organ Donation after Assis
icide/Euthanasia." Bringing the patient perspective to this complex ethical debate, Da
hlighted the importance of dignity, informed choice, and trust in healthcare systems.

Read the news

NEWSLETTER



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AstraZeneca

Boehringer Ingelheim

CSL Vifor

DIAVERUM

NOVARTIS

VERTEX

Official collaborators

bookdialysis.com

HANSA BIOPHARMA

Corporate collaborators

astellas

KREW Camp collaborators

Chiesi





THANK YOU

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