EUROPEAN KIDNEY PATIENTS' FEDERATION

SHAPE 2025

Supporting Health, Advocacy, Prevention, and Education in Kidney Care

EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR

Uniting for Kidney Health:
Empowering Lives, Enhancing Futures



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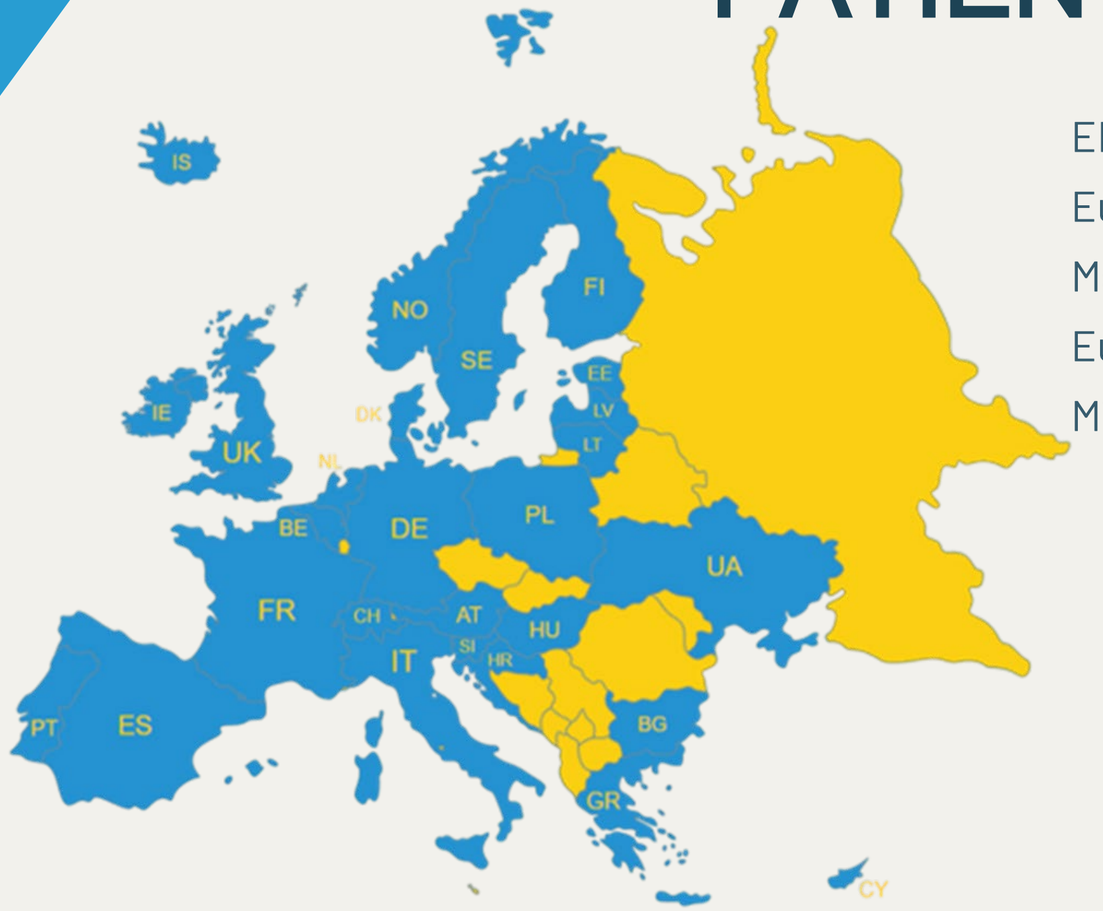
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EKPF represents around 100 million individuals with kidney conditions across Europe.

Membership includes 27 national kidney patient federations from 26 European countries.

Mission and Vision:

- Voice - Amplifying the patient's perspective.
- Choice - Promoting freedom of treatment options.
- Involvement - Enhancing patient participation in healthcare decisions.
- Safety, Autonomy, Quality of Life - Protecting patients' rights and well-being.
- Innovation and Research - Advocating for cutting-edge solutions in kidney care.

KEY FOCUS AREAS

Advocacy,
Prevention,
Collaboration,
Innovation

STRATEGIC VISION

Our approach to shaping kidney care policy and patient education



OUR TEAM



Jan Van Cruchten
Secretary



Daniel Gallego
President



Lars Skar
Treasurer



Juan Carlos Julián
Action Plan Responsible



Sari Hogstrom



Emily Groutidou - Petridou
Vice President



Hakan Hedman



Mónica Suengas
EKPF Manager



GOALS

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GOALS

- **Advocacy and Representation:** Ensure kidney patients' voices are present in policy-making processes at both national and EU levels.
- **Patient Involvement**: Equip patients with knowledge and tools to take control of their kidney health through educational resources and events
- **Prevention and Early Detection:** Increase awareness campaigns targeting the general public and high-risk groups, focusing on lifestyle changes and early intervention.
- **Choice of Treatment:** Advocate for fair access to kidney replacement therapies, including transplantation and home therapies
- **Rare and genetic Diseases:** Advocate for increased awareness and support for people affected by rare and genetic kidney diseases.

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OBJECTIVES

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Promoting Autonomy in Healthcare Decision

Strengthen patients' abilities to choose their treatment paths through shared decision-making.

Innovative Research Support

Foster collaboration in research projects that focus on different areas such as preventing kidney disease, delaying progression, rare and genetic diseases, etc.

Youth Engagement

Empower younger generations with targeted initiatives, such as youth camps, to foster long-term health advocacy and awareness

Diversity and Inclusion

Ensure that all kidney patients, including those from ethnic minorities and rare kidney disease groups, have equitable access to care and support. Advocate for tailored resources and solutions.

ACTIONS



ACTIONS



POLICY LOBBYING

Continue efforts to engage with European and international policymakers, advocating for kidney disease prevention and early detection. Execute strategic lobbying actions, such as meetings with European MEPs, to raise kidney conditions to EU and International Agenda.



ADVOCACY CAMPAIGN

Launch targeted campaigns to raise kidney health awareness in collaboration with EKPF members, focusing on identifying key topics of importance and joining forces with various awareness days to amplify the impact of our messages



KREW CAMP

Build on the successful CAMP KREW initiative, expanding international participation and creating new workshops on health management for teenagers with kidney conditions. Try to reach more countries among our member federations.

ACTIONS

RESEARCH COLLABORATION Foster partnerships with different entities to advocate for kidney patient participation in projects funded by the European Commission.





TRAINING AND EDUCATION: Creation of educational materials that are of interest to the kidney community. Materials should be translated so EKPF members can use it in their local networks.

RARE AND GENETIC KIDNEY DISEASES: Advocate for increased awareness and support for people affected by rare and genetic kidney diseases. Collaborate with partners to develop resources tailored to the specific needs of these individuals.





LOBBY ACTIONS

1

RECOGNITION IN EUROPEAN HEALTH POLICIES AND INITIATIVES

Advocating for kidney health to remain a priority in both EU and international healthcare discussions, ensuring policymakers recognize the importance of addressing kidney conditions.

2

PROMOTING EARLY DETECTION AND PREVENTION OF CKD

Strengthen efforts to include Chronic Kidney Disease (CKD) in public health strategies, with a special focus on increasing early detection and prevention through strategic campaigns and collaborative research.

3

BUILDING STRATEGIC PARTNERSHIPS

Deepen collaborations with key institutions like the European Commission and the World Health Organization (WHO) to drive forward innovative policies and programs that support kidney health at European level.

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KREW CAMP

KREW
EKPF CAMPUS

Involving Adolescents

Helping young kidney patients develop autonomy and responsibility in managing their condition. This empowerment encourages them to take ownership of their health journey and become more proactive in their care.

Fostering Connections

The camp offers a unique opportunity for adolescents to connect with others who are going through similar experiences. This shared environment promotes emotional support, reduces feelings of isolation, and builds a sense of community.



Collaboration among entities

International initiative among various member federations. By bringing together different organizations, the camp promotes the exchange of ideas, best practices, and shared experiences. This collaboration offers participants a diverse and enriched environment.

COMMUNICATION AND DISSEMINATION

Strengthen EKPF's communication strategy, ensuring impactful engagement with the kidney community and stakeholders.

Actively research and engage with EKPF members and the wider community to determine the most relevant and pressing topics in kidney health. Use this feedback to shape our communication efforts

Join Awareness days. Raise our voice to send messages about prevention and early detection. Always provide the patient's perspective





SOCIAL MEDIA ENGAGEMENT

LinkedIN
EKPF- European Kidney Patients' Federation

X (Twitter)
@EKPFpatients

Facebook
@EKPFceapir

Instagram
@ekpf_oficial

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eKPF EUROPEAN KIDNEY PATIENTS' FEDERATION

NEWSLETTER

SEPTEMBER 2024

www.ekpf.eu



KitNewCare Video

We're excited to present the KitNewCare project video! Explore the innovative solutions we are pioneering to kidney healthcare, making it more sustainable for the environment. This video highlights our commitment to creating a greener future and the strength of our consortium's collaboration.

Check the website

We need to talk about living with kidney cancer

World Kidney Cancer Day | 15 June 2023

The World Kidney Cancer Day 2023 campaign has kicked off

This year's theme, "We need to talk about living with kidney cancer," highlights the importance of addressing the challenges faced by patients. One significant challenge is maintaining a good quality of life. The campaign aims to share experiences and tips from patients and caregivers worldwide, offering support for physical and mental well-being. Regardless of age or stage, it is crucial to initiate discussions about living with kidney cancer. Join us and be part of the

KREW

EKPF CAMPUS 2023

KREW Camp

Our KREW camp is expanding and making fantastic progress. With participants already joining us from Poland, the Netherlands, Spain, and Greece, we eagerly anticipate the addition of more countries to our diverse community. As we finalize our team of leisure and nurse professionals, we are also putting the finishing touches on an exciting lineup of activities and workshops. Get ready for an unforgettable camp experience filled with adventure, creativity, and personal growth at Camp KREW

Newsletter

MANIFESTO

Keep updating our Manifesto

Incorporate the changes and improvements we have made and validate them at the General Assembly each year

Share it with members and stakeholders

Make the manifesto accessible to all stakeholders, from patient groups to policymakers, ensuring it is used as a key tool in advocacy efforts



The Manifesto serves as our foundational guide, outlining the core principles that shape and direct our action

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COLLABORATORS

Premium collaborators

Amount of the Sponsorship: **25.000€**

It entitles sponsors to:

- **Appear in all official SHAPE campaign** documents with their official logo, labelled as “Premium sponsor". This includes webinars, webinar reports, official EKPF website, printed and online documents for the Annual Summit and Awareness Days, and mention at the EKPF General Assembly.
- **Participate as a speaker at EKPF Annual Summit**, with a 20 minutes presentation.
- **Official sponsor of the KREW Camp** and appear in the all dissemination materials about it.
- **Include PRINTED INFORMATION in the official documentation** of the Annual Summit, General Assembly and the Updated Manifesto.
- **Propose topics for WEBINARS** or project on common goals with EKPF.
- **Propose the organization of FOCUS GROUP** with patient representatives on a common goal with EKPF.





Official collaborators

Amount of the Sponsorship: **15.000€**

It entitles sponsors to:

- **Appear in all official SHAPE campaign** documents with their official logo, labelled as “Official sponsor". This includes webinars, webinar reports, official EKPF website, printed and online documents for the Annual Summit and Awareness Days, and mention at the EKPF General Assembly and the Updated Manifesto.
- Propose the **organization of FOCUS GROUP** with patient representatives on a common goal with EKPF.
- **Propose topics for WEBINARS** or project on common goals with EKPF.
- **Official sponsor of the KREW Camp** and appear in the all dissemination materials about it.
- **Participate at EKPF Annual Summit,** but not as a speaker.*

*Only Premium Sponsors will be entitled to participate as speakers

Corporate collaborators

Amount of the Sponsorship: **7.500€**

It entitles sponsors to:

- **Appear in all official SHAPE campaign documents** with their official logo, labelled as “Corporate sponsor". This includes official EKPF website, printed and online documents for the Annual Summit and Awareness Days, and mention at the EKPF General Assembly.





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