EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION
CEAPIR

Uniting for Kidney Health:
Empowering Lives, Enhancing Futures

REACH

Renal Education, Advocacy, Collaboration and Kidney Health

2024



CONTENT

01 About Us

02 Our Team

03 Objectives

04 Actions

05 Development of the activities

06 Collaborators

European Kidney Patients Federation



EKPF represents over **75 million of people** with kidney health conditions in Europe.

Its membership brings together **27** national kidney patients federations from **26** different countries across Europe.

Its mission is to improve:

- Voice
- Choice
- Involvement
- Safety
- Autonomy
- Quality of life
- Innovation and research

EKPF
EUROPEAN KIDNEY PATIENTS' FEDERATION

Our team



Daniel Gallego
President, Spain



Jan Van Cruchten
Secretary, the Netherlands



Emily Groutidou-Petridou
Vice-president, Cyprus



Lars Skar
Treasurer, Norway



Sari Hogstorm
Board Member
Finland



Hakam Hedman
Board Member
Sweeden



Juan Carlos Julián
EKPF Action Plan
Responsible



Mónica Suengas
EKPF Manager

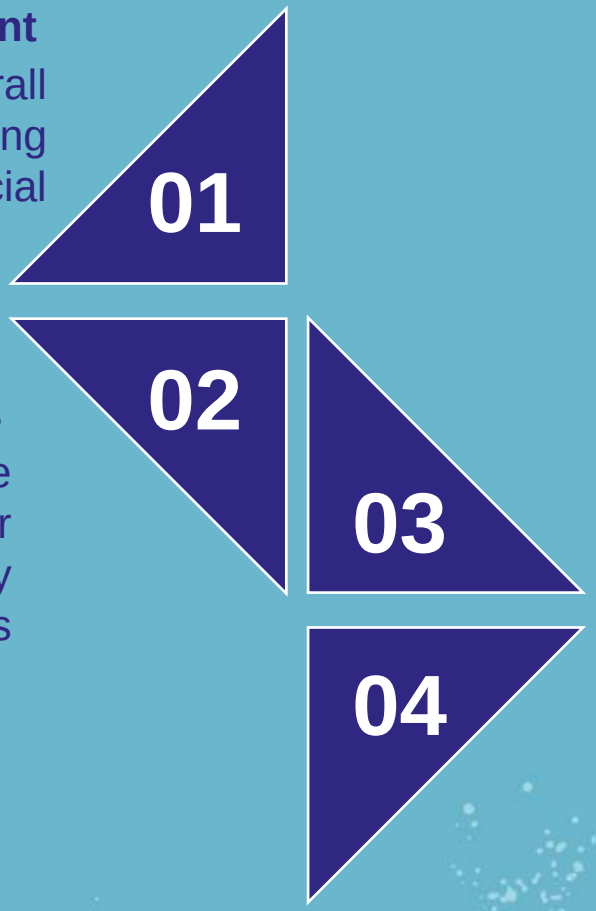
OBJECTIVES

Quality of Life Enhancement

Develop initiatives to improve the overall quality of life for kidney patients, addressing not only medical needs but also psychosocial and emotional support.

Advocacy Awareness

Empower kidney patients to become advocates for their rights, ensuring their voices are heard in healthcare policy decisions and promoting equitable access to treatment and care.



Promote Prevention and Early Detection

Reaching not only people living with kidney conditions, but also high risk groups and general population. Collaboration in projects, research and papers to promote activities related with Prevention and Early Detection.

Education Promotion

Develop and disseminate educational materials to kidney patients and the general population, focusing on prevention, early detection, and kidney health management.

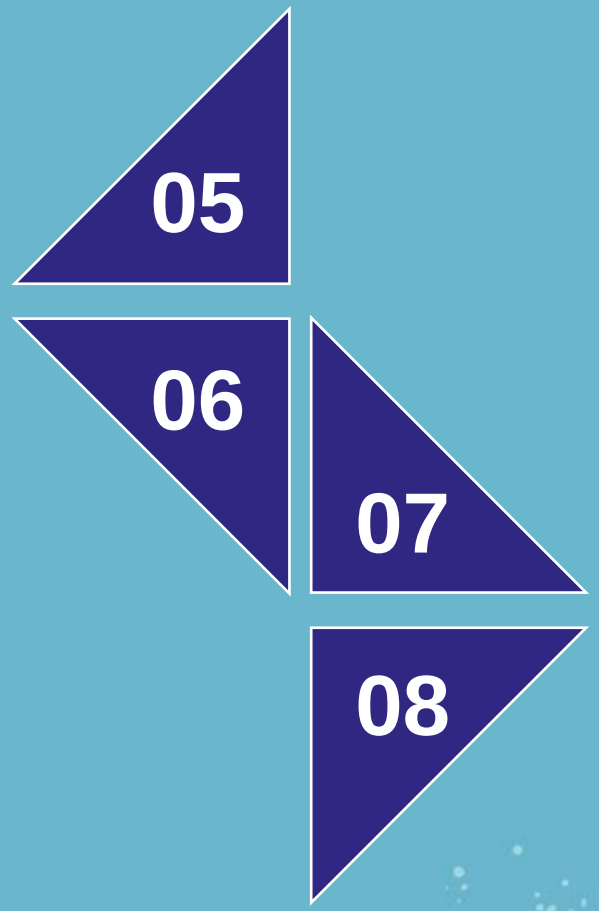
OBJECTIVES

Mobility

Encourage and facilitate kidney patients to have free movement to travel abroad. Facilitate mobility of people with kidney disease across Europe in any KRT, even in dialysis and/or waiting list for kidney transplant

Access to transplantation

Promote improved access to kidney transplantation. Advocate for policies and initiatives that reduce barriers to transplantation, foster collaboration among healthcare stakeholders, and raise awareness about the importance of organ donation.



Choice of treatment

Providing comprehensive information about all possible kidney replacement therapies. Promote shared decision making to ensure kidney patients are empowered to make informed choices about their treatment options, including home dialysis.

Managing the progression

Raise awareness about the importance of early detection, regular screening, and lifestyle to slow down the progression of kidney disease. Advocate for policies and initiatives that support research into innovative treatments and therapies designed to delay the progression of the disease.

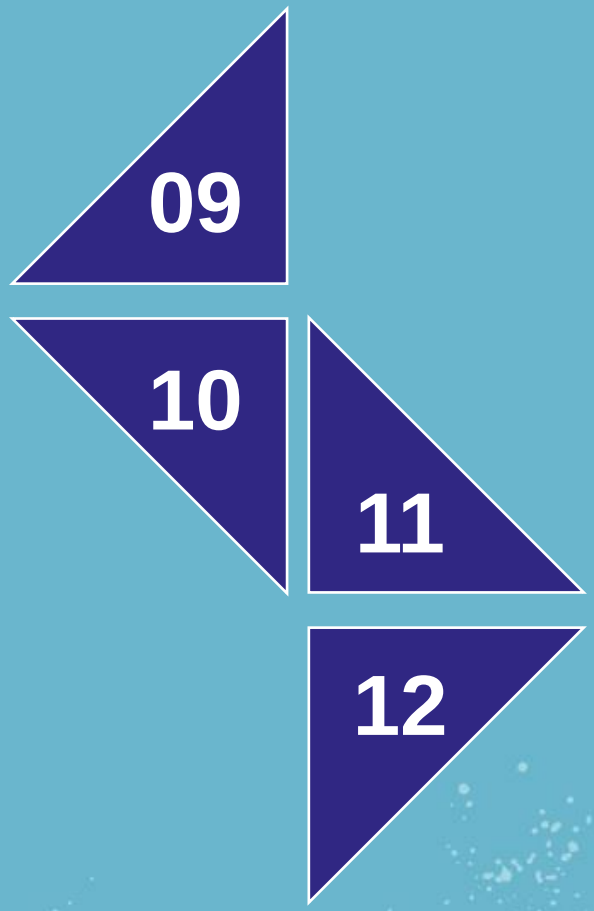
OBJECTIVES

Diversity and Inclusion Initiatives

Addressing the unique challenges faced by rare kidney disease patients, as well ethnic minorities within the kidney patient community, ensuring equitable access to healthcare and support services.

Engaging Younger Generations

Engage younger populations in kidney health awareness initiatives, encouraging them to raise their voices and play an active role in advocating for kidney disease awareness and prevention.



Stakeholder Collaboration

Foster joint actions and partnerships with various stakeholders to collectively address the needs of kidney patients and work towards common objectives.

Support Network Building

Promoting interaction among patient organizations at the European level, among EKPF members and also with different entities and collaborators.

ACTIONS

Camp KREW

Continue with this important activity, improving activities and workshops, offering and amazing opportunity for teenagers with kidney diseases. Collaboration with EKPF members and stakeholders.

Working groups

Review and enhance the efficiency of EKPF working groups, fostering active collaboration and the production of valuable resources for the kidney community.

Awareness Days

Organise awareness campaigns among EKPF members, focusing on key topics related to kidney diseases, and utilize digital platforms and social media to reach a wider audience.

Lobby Actions

Execute strategic lobbying actions, such as meetings with European MEPs, to raise kidney conditions to EU and International Agenda.

ACTIONS

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.

European Project Collaboration

Encourage active patient participation in research and collaborate with partner entities to present joint projects to the European Commission, leveraging European funds and resources to develop impactful activities.

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.

EKPF Manifesto

Review and revise the Manifesto to reflect the evolving needs and priorities of EKPF. Consult with members to ensure it encompasses the current challenges and goals and present it to advocate for meaningful changes and support.

KREW Camp

EKPF CAMPUS



Kidney Recreation and Education Week

The aim is to reach adolescents, who are candidates for two or three transplants in their lifetime, and to educate them to be more empowered in the future.

- Participation of at least three EKPF members to ensure the internationality of the camp.
- Teenagers aged 13 to 17 years old, with minimal age differences to maintain group homogeneity.
- Groups are accompanied by a nurse and a representative to ensure the safety of trips and during the camp.
- We need the active involvement and voices of the younger community to enhance the quality of life for individuals living with kidney conditions.

Lobby Actions

World Health Organization

EKHA EUROPEAN KIDNEY HEALTH ALLIANCE

European Commission



- Continue efforts to raise awareness among policymakers, advocating for kidney conditions to be prominently featured on the EU and international healthcare agendas.

- Promote Chronic Kidney Disease (CKD) on the European public health agenda and actively advocate for the advancement of early detection and prevention measures.

- Sustain collaborations with the EU Commission and the World Health Organization (WHO) to advance kidney health initiatives and policies.

This "Lobbying for Kidney Health Advocacy" action will help position EKPF as a leading advocate for kidney health and ensure that kidney-related issues remain a priority on the EU and international agendas.

Working groups



Strengthening

Improving the already existing strategy to stregthen the working groups, creating new ones with diverse entities. Implement innovative and collaborative mechanisms to enhance group synergy.



Topics

Select topics of particular relevance and interest together with members for the establishment of educational groups and materials. Ensure máximum impact of the working groups.



Content

Develop a range of educational materials and ensure that are accesible and relevant to all entitites. Materials can be designed in different formats to ensure the goals.



Multilingual Dissemination

Implement a strategy for translating and disseminating documents in multiple languages. Facillitate collaboration with entities to ensure the materials can be used at a national level.

Communication and Dissemination

Maintain active social media profiles

Promote interaction among members

Maintain our website updated Ekpf.eu

Newsletter



Communication and Dissemination

- **Newsletter**
- **Official website: ekpf.eu**
- **Social Media Profiles:**

EKPF - European Kidney Patients' Federation

@EKPFpatients

@ekpf_oficial

European Kidney Patients' Federation



Awareness days

World Kidney Day

World Kidney Cancer Day



I SUPPORT RARE DISEASE DAY

aHUS Awareness Day

Sept 24

PKD AWARENESS DAY SEPT.4

- Raise our voice to send messages about prevention and early detection
- Talk about the problems and needs of kidney patients
- Join National, European and International campaigns
- Collaborate with members to make messages more powerful
- Always provide the patient's perspective

Manifesto

- Keep updating the manifesto
- Reach as many people as possible, both entities and collaborators
- Share it among the member entities so they can also share it
- Use it as a cover letter to show our claims and interests
- Have meetings/webinars with all members to keep updating it



COLLABORATORS

Premium

Amount of the Sponsorship: **25.000€**

It entitles sponsors to:

- **Appear in all official REACH 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

Amount of the Sponsorship: **15.000€**

It entitles sponsors to:

- **Appear in all official REACH 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,** <u>but not as a speaker</u>.*

*Only Premium Sponsors will be entitled to participate as speakers

Corporate

Amount of the Sponsorship: **7.500€**

It entitles sponsors to:

- **Appear in all official REACH 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.

Thank you



Uniting for Kidney Health:
Empowering Lives, Enhancing Futures