

EUROPEAN KIDNEY PATIENTS' FEDERATION

EKPF
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CEAPIR

MANIFESTO

This manifesto is a dynamic document that serves as a call to action. We invite all institutions, healthcare professionals, patients, and European citizens to join us in the fight for the rights of kidney patients, so they can live with dignity, health, and hope. For a future free from chronic kidney disease.

Ratified at the General Assembly on October 18, 2024

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VOICE



01

RAISE AWARENESS OF KIDNEY DISEASE

Kidney disease is a silent killer. Increase the visibility and knowledge about CKD is crucial in the general population, so we need to address CKD in EU policy, promoting education and healthy habits through educational programs.





RISK GROUPS

Certain populations are at a higher risk of developing kidney diseases, such as individuals with diabetes, hypertension, or obesity. Most people in these risk groups do not realize they are vulnerable to kidney disease until it has advanced. We aim to reach these risk factors to delay CKD progression.

PREVENTION AND EARLY DETECTION

Timely detection is essential for effective management and treatment. Most people do not know they have kidney disease because it often exhibits no symptoms in the early stages. We can make a significant difference in the lives of individuals at risk by identifying kidney diseases at their earliest stages.




TREATMENT
02

CHOICE OF TREATMENT

Information on all possible kidney replacement therapies (KRT), including conservative management and promoting home therapies. Shared decision-making ensures kidney patients are choosing freely the best treatment options for their lives.





ACCESS TO TRANSPLANTATION

Increase organ donation and the social protection of living donors, to facilitate the access to kidney transplants in all countries, reducing the waiting list, overcoming barriers and working against organ trafficking.

GENETIC TESTING

Advances in genetic testing can help diagnose inherited kidney diseases early, offering personalized treatment options and guiding shared decision-making for KRT.





ETHNICAL MINORITIES & CULTURAL DIFFERENCES

Ethnic minorities may have a higher prevalence of CKD due to genetic predispositions and face barriers to healthcare, such as language, insurance, and location. Cultural beliefs about health can influence behaviors, leading to later diagnoses and poorer CKD outcomes.


INVOLVEMENT
03

EDUCATION AND SELF CARING

The key to supporting patients is education, so we need to promote access to reliable sources of information about kidney disease, healthy habits, and best practices.





SOCIAL IMPERATIVES AND PROTECTION

Improving and increasing socio-laboral protection for kidney recipients and living donors. Ensure equitable access to all KRT options.

INVOLVEMENT

INCLUSIVE ENGAGEMENT

It's essential to involve all patients in the decision-making process, including ethnic minorities, those with disabilities, and people from different cultural backgrounds. Understanding and addressing their specific needs ensures that KRT and kidney care are equitable and culturally sensitive.





SAFETY

04

VULNERABLE GROUPS

Kidney patients in dialysis and kidney recipients using immunosuppression, should be regarded as a high-risk group. Many of them are elderly and have impaired kidney function and other co-morbidities that increase the risk of adverse outcomes.





ANTIMICROBIAL RESISTANCE (AMR)

AMR is an increasingly serious public threat, risking the effective protection and treatment of infections. Appropriate use and abuse of anti-infectives by kidney patients requires concerted efforts by us.

SAFE TREATMENT OPTIONS

Ensure that patients have access to safe and effective treatment options, including home therapies, regardless of external factors like pandemics, public facilities and transportation.




AUTONOMY
05

UNIVERSAL ACCESS

Kidney Replacements Therapies (KRT) universal coverage for treatment options and medication that reduce the probability or slow down the progression of chronic kidney disease. Adequate reimbursement policies and strategies must cover all people with kidney conditions.





MOBILITY

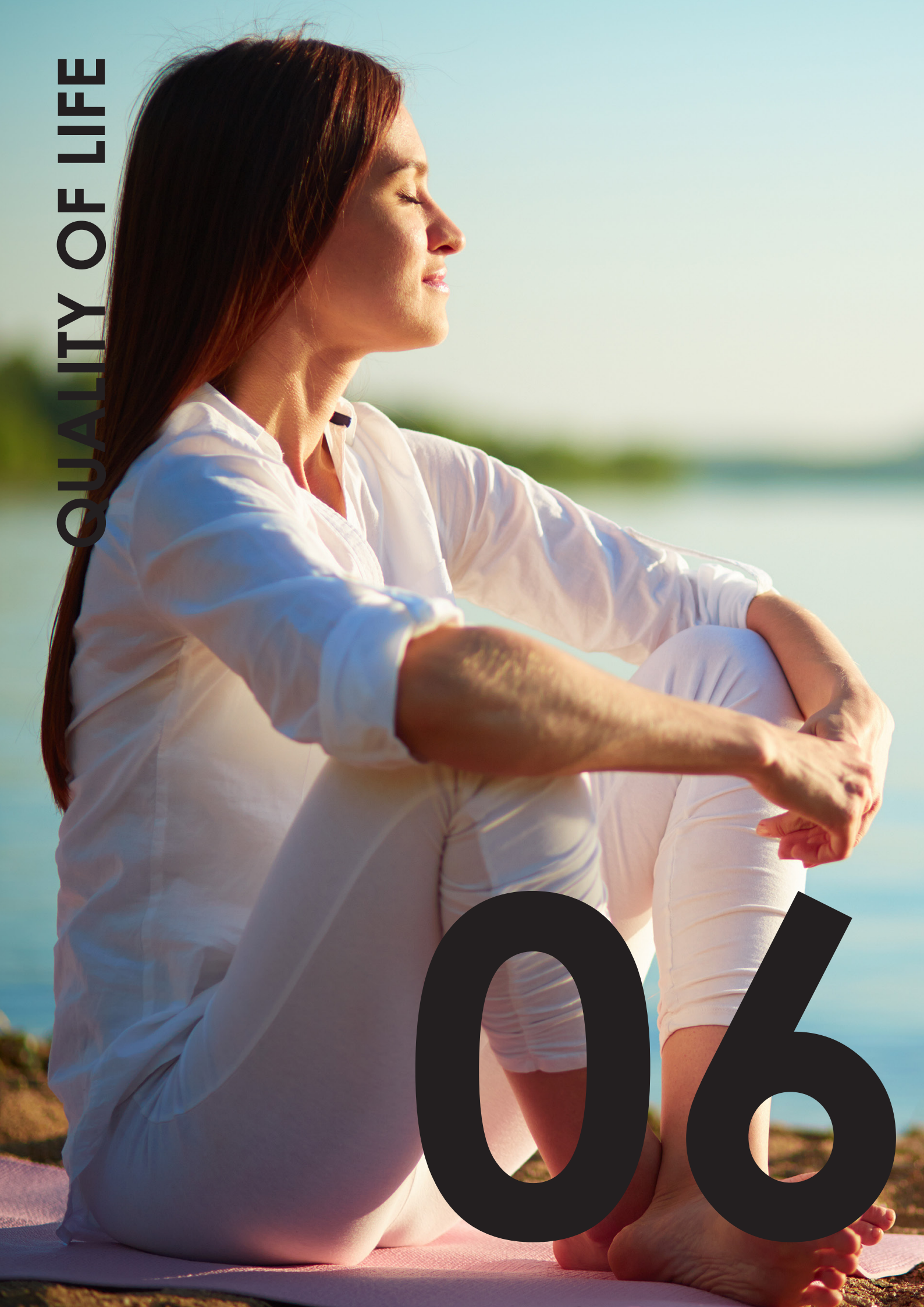
Facilitate mobility of people with kidney disease across Europe in any KRT, even in dialysis and/or waiting list for kidney transplant. Holiday dialysis programs should allow kidney patients free movement in and out Europe area.

AUTONOMY

EMPLOYMENT

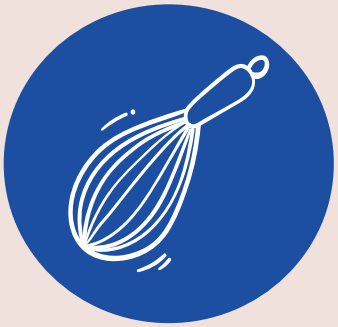
Working is profoundly important to many people with kidney chronic conditions. It can help them to have a feeling of value to society and themselves. Facilitate access to employment in any stage of kidney disease. and kidney transplant.




QUALITY OF LIFE
06

NUTRITION AND PHYSICAL ACTIVITY

Nutrition is crucial for managing kidney disease and maintaining overall health. Making healthy food choices is important for everyone, but it is even more essential for those with kidney disease. Educating patients by providing resources and tools can help them manage their physical activity effectively and avoid sedentary habits while still enjoying a satisfying diet.





UNMET SYMPTOMS

Addressing the humanistic burden of kidney disease requires identifying and paying greater attention to unmet symptoms such as pruritus, anemia, pain, fatigue, sleeplessness, and mineral and bone disorders.

VASCULAR ACCESS/PD CATHETER

Promote and inform about the importance and proper management of vascular access for hemodialysis and catheter for peritoneal dialysis to optimize the care of the person living with kidney disease. The focus should not only be on the vascular access or catheter itself, but on the person with kidney disease.





SEXUAL HEALTH

Sexual health is an important part of life and means more than sex, it's physical, emotional, mental and social well-being in relation to sexuality. You are not alone, sexual health problems are common in kidney disease and you should not feel embarrassed about discussing this with your care team as this is an important aspect of your quality of life.

RESEARCH



07

MEASURING PATIENTS' PERSPECTIVE

Health-related quality of life is crucial for patients with chronic kidney disease. It should be complemented by measures of perceived experience (PREMs) that help explain outcomes and allow for interventions to improve quality of life.





ARTIFICIAL INTELLIGENCE AND BIG DATA

Integrating patient perspectives data, measurements and outcomes into AI algorithms and big data analysis helps interpret clinical results and supports patient-centered decision-making in chronic kidney disease (CKD) management.

RARE KIDNEY DISEASES

Raising awareness and improving research on rare kidney diseases is vital for advancing clinical knowledge, training, early diagnosis, prevention, and treatment options for patients affected by these conditions.



INNOVATION



08

EQUITABLE ACCESS TO NEW TREATMENTS

Ensure all kidney patients have equal access to the latest advancements in treatments and therapies, regardless of geographic location or socioeconomic status. This includes access to cutting-edge technologies, personalized medicine, and innovative kidney replacement therapies (KRT).





PROMOTING RESEARCH AND DEVELOPMENT

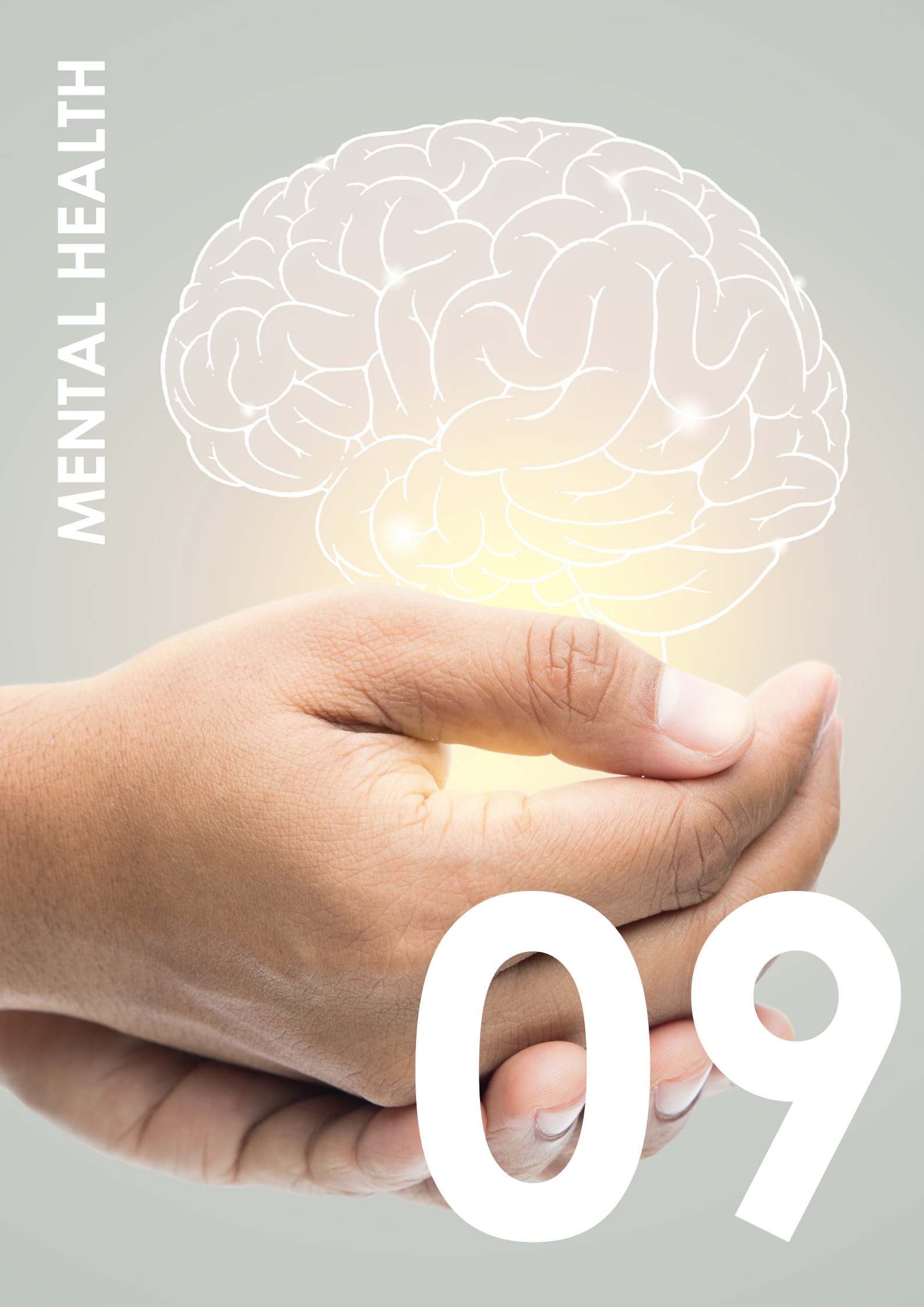
Encourage investment in research for innovative solutions, including AI-driven data analysis, genetic testing, and new treatment modalities. Advancing clinical knowledge in chronic and rare kidney diseases is crucial for developing more effective and personalized care options.

PATIENT-CENTERED INNOVATION

Innovation must be guided by patient needs and perspectives. Incorporating patient-reported outcomes (PROMs) and experiences (PREMs) in research and innovation processes ensures that new treatments improve not only clinical outcomes but also patients' quality of life and overall well-being.



MENTAL HEALTH



09

OVERCOMING BARRIERS

Maintaining good mental health can be challenging for people with kidney disease. Stressors related to their condition can impact their overall well-being.





ACCEPTANCE AND POSITIVE COPING

Health systems must recognize mental health conditions and promote acceptance of lifelong conditions. We must promote coping strategies that offer better perspectives on the disease, maximizing the perceived quality of life

PSYCHOLOGY SERVICES

Psychology services play a vital role in the management of CKD. The psychological impact of CKD can be significant, so facilitating access to report and treat mental health conditions, should be addressed by health professionals.



ECOLOGY



10

PLANET-FRIENDLY MEASURES

With the majority of kidney failure patients on dialysis, ecological optimisation is imperative and must be pursued from production to delivery and waste management. Several industry stakeholders are taking planet-friendly measures to-reduce climate change.





REDUCTION OF POLLUTANT PRODUCTION

Energy consumption is multifaceted and includes the manufacture of filters, machines and other consumables and the dialysis itself. It also includes dialysate production and heating, monitoring, lighting and climatization of the unit and the transport of material and patients, which contribute to extensive production of greenhouse gases and pollutants.

EDUCATION AND RESEARCH ON ENVIRONMENTAL IMPACTS

Raising awareness about co-friendly treatment options and their benefits for patients and the environment. Supporting research to understand how we can minimize environmental impact.





PREMIUM COLLABORATORS

Alnylam

astellas

AstraZeneca

CSL Vifor

FRESENIUS MEDICAL CARE

NOVARTIS

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