

Roundtable on ways to enhance quality of life in dialysis care

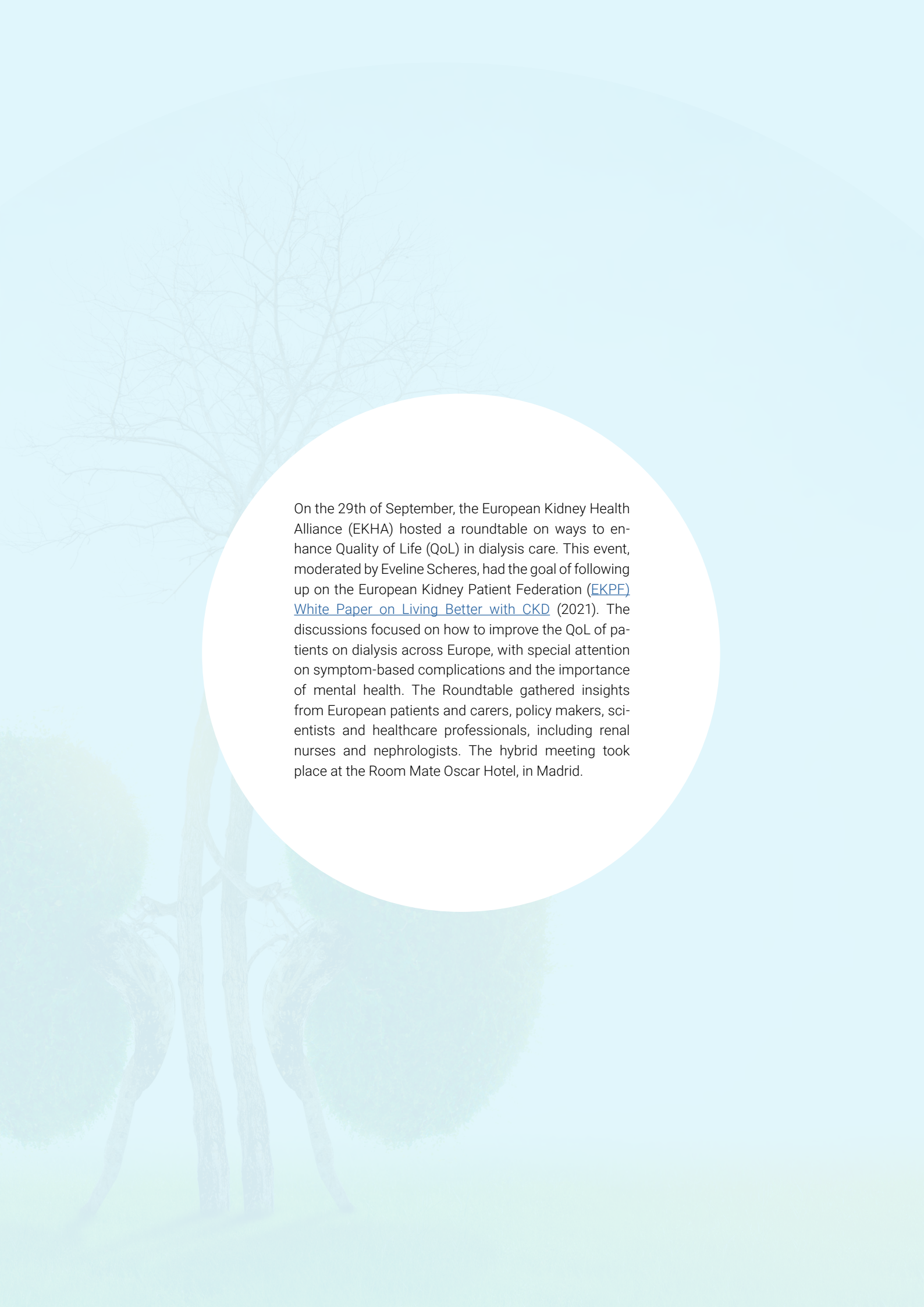
Hybrid event

29th September 2022

14:30-18:00 CEST

Room Mate Oscar Hotel, Plaza Pedro
Zero 12, Madrid, Spain & online



The background features a light blue gradient with a large, faint circular graphic in the center. To the left, there are stylized, light green trees with thin trunks and sparse foliage. The text is contained within the white circular area.

On the 29th of September, the European Kidney Health Alliance (EKHA) hosted a roundtable on ways to enhance Quality of Life (QoL) in dialysis care. This event, moderated by Eveline Scheres, had the goal of following up on the European Kidney Patient Federation ([EKPF White Paper on Living Better with CKD](#) (2021)). The discussions focused on how to improve the QoL of patients on dialysis across Europe, with special attention on symptom-based complications and the importance of mental health. The Roundtable gathered insights from European patients and carers, policy makers, scientists and healthcare professionals, including renal nurses and nephrologists. The hybrid meeting took place at the Room Mate Oscar Hotel, in Madrid.

WELCOME REMARKS



Prof. Em. Raymond Vanholder,
President of EKHA



Eveline Scheres,
EKHA general manager and moderator

Prof. Em. Raymond Vanholder, president of EKHA, and Eveline Scheres, EKHA general manager and moderator of the roundtable, welcomed participants and thanked the EKPF for their collaboration and CSL Vifor and Fresenius Medical Care for their support.

Prof. Em. Raymond Vanholder stated that QoL has “too much, and for too long, been neglected in medical circles”. He advised to listen above all to the voices of patients as they are directly confronted with the disease and its consequences.

OPENING ADDRESS



César Luena,
Member of the European Parliament, Vice-Chair of the ENVI Committee

Spanish Member of the European Parliament (MEP) César Luena, vice-chair of the Committee on the Environment Public Health and Food Safety (ENVI) in the European Parliament and member of the MEP Group for Kidney Health, sent a message of support and appreciation for EKHA's commitment to improving kidney care in Europe.

“I want you to know that from the European Parliament, and in my case as vice-chair of the ENVI Committee and as a member of the MEP Group for Kidney Health, you have all my consideration, all my support, not only for these conferences or other events, but in general for all the challenges you face. I want you to know that you are accompanied and that you have our commitment.”

INTRODUCTORY PRESENTATIONS

Key take aways from the EKPF “Living better with CKD - Improving the quality of life of CKD patients on dialysis across Europe”



Daniel Gallego,
President of EKPF

Daniel Gallego, EKPF president, shared the patients' perspective and the key takeaways from the Whitepaper. The document explores the consequences for both patients and healthcare systems of the demand for dialysis; sets out the personal, societal and economic burden; and suggests potential solutions to improve quality of life for dialysis patients.

Mr. Gallego stressed the importance of addressing the unmet needs and unpleasant symptoms of Chronic Kidney Disease (CKD) and dialysis patients. Adopting a holistic approach that tackles not only dialysis' clinical and economic burden but also the humanistic burden is crucial. To do so, Mr. Gallego shared recommendations such as

redesigning the scales that measure QoL so that they address the patients' wellbeing (both mental and social); including perception of health; and including Patient-Reported Outcomes Measures (PROMs) and Patient-Reported Experience Measures (PREMs). The paper encourages healthcare providers to also focus on symptom based complications such as fatigue and pruritus in order to provide the best possible care for patients. On this topic Mr. Gallego also presented the EKPF paper Living with CKD-associated Pruritus which highlights the impact of the condition on patients' quality of life and spoke about the paper he contributed to following a Consensus Conference on Symptom Based Complications in 2021.

Improving quality of life of CKD patients: presentation of the main findings of a recent patient survey.



Anne Stinat,
Vice-president of France Rein

Anne Stinat, vice-president of French kidney patients' association France Rein, presented the main findings of a survey on French dialysis patients and their QoL. This survey aimed to improve the knowledge of dialysis patients' life, and determining their QoL comparatively to “how and where” they receive their treatment. The overarching objective was to identify the reasons for the slow uptake of home dialysis and build the foundations for future collaboration with relevant institutions.

The survey showed that 58% of patients voluntarily chose to give up their treatment at home and go back to a dialysis facility. Home patients declared less symptoms but felt them more negatively. Although the survey only registered the responses

without offering interpretations, these findings may suggest that patients are more or less left to their fate if problems occur with home dialysis, and that care providers may benefit from more training and expert advice. Moreover, it was also found that there is a gap between the symptoms experienced by patients and the negative feelings and emotions they report (e.g., only 19% declare to suffer from hair loss but 60% declare to get a negative feeling due to hair loss).

Ms. Stinat highlighted the importance of educating patients and improving their communication with their healthcare providers so that they can, whenever appropriate not only access but also remain on home dialysis services.

How can renal nurses contribute to the QoL of dialysis patients and the shift from hospital to in-home dialysis.



Anna Marti Monros,

Renal nurse representing EDTNA/ERCA

Anna Marti Monros, renal nurse speaking on behalf of the European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA) represented the role of nephrology nursing on the improvement of the patients' QoL as a table with three legs: education of both nurses and patients, empowerment of the latter and nurses as patient advocates. She described a nurse being a patient advocate as someone who works on behalf of patients to maintain QoL, protects their rights and facilitates communication

with all members of the healthcare team regarding their preferences.

With regards to the shift from hospital to home dialysis, Ms. Marti pointed out that patients receiving home dialysis have been reporting important clinical advantages overall. However, the lack of adequate patient and caregiver education is one of the main factors that have led to the low uptake of home dialysis globally. Thus, for a successful shift, patients and carers have to be properly trained.

PANEL DISCUSSION

The presentations were followed by a panel discussion during which both the online and onsite audience interacted with the speakers. The aim of the discussion was to agree on a common set of priorities that should be taken into account when addressing dialysis patients' QoL.

The panel was formed by:



Prof. Em. Raymond Vanholder,

President of EKHA



Daniel Gallego,

President of EKPF



Anne Stinat,

Vice-president of France Rein



Anna Marti Monros,

Renal nurse representing EDTNA/ERCA



Dr. Alberto Ortiz,

Head of nephrology at Hospital Universitario Fundación Jiménez Díaz (Madrid, Spain) and chair of the European Renal Association (ERA) Registry

Prof. Em. Raymond Vanholder recalled that implementing a **shared decision making** system involving both patients and their caregivers was key to foster change. He also put the emphasis on the fact that QoL indexes should be correctly followed and published. As for advocacy, Prof. Em. Raymond Vanholder raised the importance of unity in the patient community and the use of a language that resonates with the public and with policymakers.

According to Dr. Ortiz **new technologies and electronic records** are the best way to capture PROMS and PREPS. He also underscored the importance of health data as an essential tool to inform policy decisions. As for the physician's role, he pointed out that they should provide the best care available, inform about different dialysis possibilities when appropriate, give the patient enough information to make an informed decision and monitor the quality of the care provided.

As a nurse herself, Anna Marti called attention on the importance of **educating healthcare professionals** (including **peer to peer education**) and counselling on the patients' mental wellbeing. Ms. Marti also emphasized the need to fight the stigma around dialysis and to establish a team approach individually oriented towards the patients' treatment.

On behalf of patients, Daniel Gallego insisted on the need to:

- Ask for the patients' preferences and listen to their opinions regarding treatment.
- Help health systems develop and implement tools to detect mental health problems early.
- Support patients in accepting that they have a chronic disease and alleviate their fears (70% of dialysis patients think they are going to die at the beginning of treatment).

Likewise, he also insisted on the need to adopt a **patient-centric approach** and to humanize healthcare systems. On the other hand, Anne Stinat insisted on the importance of explaining all types of dialysis treatments available to patients, easing communication with their healthcare team and encouraging them to open up and speak to their caregivers and family about their struggles.

Both on-site and online participants had the opportunity to engage with the speakers and contribute to the discussion, either by asking questions or making comments. The points **raised by the audience** revolved around four main issues/ideas:

1. **Patient advocacy** is instrumental in improving kidney care. As such, patients must be included in advocacy efforts to raise awareness of their needs.
2. **Complete psychosocial care**, which gives access to social workers and psychologists, also contributes to achieving a higher QoL. Family members and caretakers also need to be involved in the conversation.
3. **A patient-centric approach** puts patients in control over aspects that influence their QoL. A patient-centric approach takes patients' needs, desires and education into account.
4. There is a need to **improve patients' health literacy**. Patients' education must be tailored to their perspective, and start at the onset of their disease (pre-dialysis).

REFLECTIONS ON THE ROUNDTABLE



Nicolás González,

Member of the European Parliament, Member of the ITRE Committee and Substitute Member of the ENVI Committee

In a video, MEP Nicolás González Casares, Member of the Committee on Industry, Research and Energy (ITRE) and Substitute Member of the ENVI Committee, offered reflections on the impact dialysis has on the patients' QoL and on how to improve it. As a healthcare professional, he is fully aware of the difficulties faced by patients suffering from kidney disease. He called for more visibility, easy and

equal access to dialysis services and better coverage of treatments, including both physical and psychological aspects. In this sense, he pointed out that the European Union can support Member States in sharing best practices and increasing investment in research to advance the development of innovative treatments for kidney diseases.

CLOSING OF THE ROUNDTABLE



Prof. Em. Raymond Vanholder,

President of EKHA

Prof. Em. Raymond Vanholder thanked the panelists and participants for contributing to the debate and highlighted the key messages of the event:

- There is an urgent need to listen to and empathize with patients.
- Both patients and healthcare professionals should receive proper education on CKD and dialysis.
- Patients should play a more active role in advocating for the improvement of their QoL and should speak with one voice.

Prof. Em. Raymond Vanholder concluded by calling on the European Union and Member States to work together to develop a patient-centered approach to dialysis care.



This roundtable was supported by:

CSL Vifor



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 EKHA - European Kidney Health Alliance

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