# World Kidney Day 2023

## Preparing for the unexpected, supporting the vulnerable

**Conversation with:**

- **Mr. Daniel Gallego,** President, European Kidney Patients' Federation
- **Prof. Dr. Dmytro Ivanov**, President, Ukrainian Association of Nephrology
- **Prof. Dr. Z. Serhan Tuğlular**, Chair, Renal Disaster Relief Task Force of the European Renal Association
- **Prof. Em. Raymond Vanholder,** President, European Kidney Health Alliance

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Adverse effects of both natural (earthquakes, hurricanes, pandemics) and man-made disasters (wars, terrorist attacks, nuclear plant accidents) have been experienced or are still being experienced (e.g. the COVID-19 pandemic, Pakistan flooding, US Hurricane Ian, the Syrian and Russian-Ukrainian wars, and most recently, the devastating earthquakes in south-east Turkey and north-east Syria). Although some regions are at higher risk, no place around the globe is exempted of disaster threats.

World Kidney Day 2023 theme *'Preparing for the unexpected, supporting the vulnerable'* highlights the significant impact of disastrous events on the kidney community. Disasters result in serious disruptions of the functioning of a society causing widespread human, material, economic or environmental losses.

Prof. Em. Raymond Vanholder, Prof. Dr. Dmytro Ivanov, Prof. Dr. Serhan Tuğlular, and Mr. Daniel Gallego discuss how and why those affected by kidney disease are particularly affected by disaster situations, as well as their needs in times of crisis.

EKHA EUROPEAN KIDNEY HEALTH ALLIANCE

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***How are kidney health and disasters linked?***

**Prof. Dr. Serhan Tuğlular**
The links between kidneys and disasters have been long-known. The condition 'crush syndrome'*, resulting in Acute Kidney Injury (AKI), was first defined in 1941 after the London Blitz. AKI often occurs during earthquakes and bombings when people are trapped under the rubble.
Today, we know that disasters affect the whole spectrum of kidney patients, but especially Chronic Kidney Disease (CKD) patients on kidney replacement therapies (KRTs, i.e. dialysis and transplantation). Dialysis patients are heavily reliant on medical infrastructure because they need access to running water and electricity, which may be compromised in disasters. They may have to delay dialysis sessions. For instance, in Ukraine, a quarter of CKD patients experienced delays or shorter dialysis sessions. Access to medication may also be disrupted, which can particularly affect transplant patients who are in constant need of immunosuppressants.

**Prof. Em. Raymond Vanholder**
Dialysis units may be scarce if infrastructure has been destroyed. This creates further challenges when there is an overflow of AKI patients taking the places of CKD patients in dialysis units.

**Mr. Daniel Gallego**
The COVID-19 pandemic and other disasters have shown the high vulnerability of patients with kidney diseases. CKD patients were unable to isolate during the pandemic because they needed to go to a dialysis centre multiple times per week and consequently increased their risk of infection. During wars and natural disasters, hemodialysis patients do not know if they will be able to dialyse the next day. This creates a horrible sense of uncertainty and fear about the future.

***Turkey and Syria have recently been struck by devastating earthquakes whilst the war is still raging in Ukraine. How is the situation on the ground for kidney patients?***

**Prof. Dr. Dmytro Ivanov**
In Ukraine in the last year, there have been issues in terms of logistics – in the supply of medicines like immunosuppressants, in the access to electricity and water for dialysis – but at the moment dialysis is provided in full to all patients. We even have an excess capacity of above 1,500 patients, which was not the case before the war. This is probably due to the emigration of patients to European countries. We also saw an increase in the number of transplantation, as a means to take people off dialysis.

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*Crush syndrome is a medical condition that occurs after a crushing injury of the skeletal muscles. It predominantly affects the kidneys leading to Acute Kidney Injury. Crush syndrome occurs commonly in earthquakes or bombings, when individuals have been trapped under collapsed buildings.

**Prof. Dr. Serhan Tuğlular**
At the start of the war, there were about 10,000 patients on KRTs in Ukraine. Now there are about 8,500 patients. We know that about 700 have been displaced in Europe but we do not know about the rest, if they died or are lost somewhere.
In Turkey, about 50,000 citizens died in the earthquake and about 108,000 sustained injuries. We expect about 2,000 of the injured to have crush syndrome. As for the infrastructures, multiple state hospitals and dialysis centres collapsed or had their water systems impaired in the first earthquake. At the start, the aim was to relocate CKD patients to usable dialysis centres, to make space for AKI patients in operational state hospitals. But when more dialysis centres collapsed in the second earthquake, both patient groups had to go to the same few remaining hospitals and centres. It is a very dynamic situation where you need to reorganize every day.

***In September last year, President Joe Biden declared the COVID-19 pandemic over. Is it that simple for kidney patients?***

**Mr. Daniel Gallego**
We are an immunocompromised group and the first COVID-19 wave was a tragedy for us, with more than 20% mortality in CKD patients. Today, CKD patients received at least four COVID-19 vaccine doses but are not fully protected, social distancing is still recommended as well as wearing face masks. For us the COVID-19 pandemic is not over, and that is why we are calling for European and national vaccination plans and better preparedness against new COVID-19 variants.

**Prof. Em. Raymond Vanholder**
Indeed, vaccination is not very efficient in dialysis and transplant patients and we have no solution for that. It is a long-standing issue that kidney patients are excluded from drug trials, yet they represent an important population.
It is very likely that long-COVID will affect kidneys as well but we do not know the numbers yet. In the acute phase of COVID-19 too the healthcare community did not focus on the impact on kidneys until late. Even when it became clear that kidney patients were particularly at risk, people continued to focus on other well-known chronic diseases.

**Mr. Daniel Gallego**
There is also a big impact on patient's mental health, having lost so many fellow patients to COVID-19 and living in constant fear of infection. Many patients are still reluctant to let go of face masks and self-isolation, because they are afraid of COVID-19. We saw many patients with zero immune response after full doses of vaccination, so you can imagine the fear and uncertainty they must deal with.

***We live in an era of constant disasters. Whilst some can be prevented, others will continue to strike. What measures could we put forward to better protect kidney patients?***

**Prof. Em. Raymond Vanholder**
It is remarkable that in-centre dialysis patients were better off than home dialysis patients in Ukraine because they had access to electricity generators. Yet, treatment at home would be safer in a disaster situation and for that we need smaller, cheaper and more compact systems and batteries.
Overall, we need to think about new pathways to diminish the load of dialysis, which is burdensome for patients, costly for healthcare systems, and has a high environmental footprint. There are situations where dialysis cannot be avoided but then it needs to be done in a sustainable way.

**Mr. Daniel Gallego**
Indeed patients need smaller devices that are portable. In the future, we hope to see breakthroughs in this sense but we also need new types of vascular access that are permanent, without infections, and painless.
CKD should be managed at home whenever possible, especially in disasters or unexpected events. We have seen many publications and protocols in this sense in the last three years. On top of this, we need to review and update existing guidelines to adapt them to new situations and for the future. It is very important that these guidelines show that home-therapies are preferrable and safer in disaster situations.

***In the long run, how could we use these tragic events as an opportunity to improve kidney health and build more resilient kidney care practices?***

**Prof. Dr. Dmytro Ivanov**
Nephrologists and patients need clear guidelines on nephrology care when faced with disaster situations. These could also be shared with governments and healthcare professionals to inform them how to better care for patients.

**Prof. Dr. Serhan Tuğlular**
Specific actions to be undertaken are outlining the needs, creating local renal disaster relief task forces, including prevention of AKI and crush syndrome in the medical curriculum, as well as developing telemedicine. Regular updating of medical knowledge in disaster nephrology is one of the key elements for preparedness.

**Prof. Em. Raymond Vanholder**
Preparedness is very important and plans need to be made by governments. There are two issues at hand: general disaster preparedness that is applicable to all diseases and disasters, and then specific preparedness for either specific diseases or specific disasters.

**Prof. Dr. Serhan Tuğlular**
Preparedness is crucial. Disasters may occur anywhere but preparation is vital to mitigate effects, which implies planning during the disaster-free period. Collaboration between national and international nephrology societies is essential. This should also include nurses and other healthcare professionals in contact with kidney patients as well as patients themselves.
Attention should also be given to the situation of healthcare workers. At one point after the earthquake in Turkey, they had to work non-stop, sometimes for 72 hours straight, because they could not be replaced. Colleagues might have been under the rubble or their families needed help. During the first 24 hours they were quite alone. There should be plans in place to avoid this type of situation. For instance, a system that ensures that healthcare workers take turns. There must be a strict protocol in place because no one wants to go home in crisis situation, everyone wants to help but then everyone is burnt out.

***Kidney disease suffer from a lack of awareness among policy makers and the public compared with other major NCDs. How does it impact the care and management of kidney patients during emergency events?***

**Mr. Daniel Gallego**
During the COVID-19 pandemic, CKD patients were not considered as a priority group for vaccination, although they are at high risk of infection and severe symptoms. There was a lack of awareness among decision makers, at least in the beginning. It is important that governments come up with specific preparedness plans for high-risk populations in case of disasters, so they can define their needs and be ready in the future.

**Prof. Dr. Serhan Tuğlular**
In emergency situations the authorities have to take care of many things: infrastructure, shelter, water, electricity etc., and this is true for the whole population. Kidney patients are only a small part of the population and their needs can easily be overlooked. We, healthcare professionals, should advocate with kidney patients so that their voices can be heard and specific measures can be taken.

**Prof. Em. Raymond Vanholder**
Data and figures on the frequency of CKD per country exist and we must use them to convince policymakers that CKD is an important issue. Unfortunately, CKD is an elusive disease because it goes unnoticed for a long time. However, it has disastrous consequences, especially if it is detected late.
It is our responsibility as medical community, together with patients, to convince policymakers that disaster preparedness should include kidney disease. We should work with other chronic diseases in awareness-raising as we have many similar concerns. We would have a stronger voice together. We need more patient advocacy, involvement, and empowerment.

**Mr. Daniel Gallego**
***President, European Kidney Patients' Federation***

Mr. Gallego is President of the Spanish National Federation of Associations for the Fight against Kidney Diseases since 2018. He is also the President of the European Kidney Patients' Federation since 2020; Vice-president of the Spanish Confederation of Associations People with Disabilities; Member of Technical commission to develop "active patient program" in Baleares, Spain. Additionally, he is a member of the technical committee of chronic kidney disease within the strategy of addressing chronicity and the patient program's technical commission in the Balearic health system.
Mr. Gallego is a kidney patient since 1993, undergoing hemodialysis since 1995. Nowadays, in home hemodialysis treatment. He had a kidney transplant in 1998, but had early recurrence of his kidney disease, returning to hemodialysis from 2002 until today.

**Prof. Dr. Dmytro Ivanov**
***President, Ukrainian Association of Nephrology***

Prof. Dr. Dmytro Ivanov published more than 600 papers, including 25 book chapters (in Ukrainian) on clinical nephrology. He is a specialist in nephrology and pediatric nephrology, Expert of the European Union of Medical Specialists, and Honorary Doctor of Ukraine. Dmytro Ivanov has been serving as Editor in Chief of Ukrainian nephrology journal “Kidneys” since 2012, the first Ukrainian Nephrology website since 2003, annual Continuing Medical Education course at the Renal Eastern Europe Nephrology Academy since 2005 and head of nephrology department in National University. He is now President of Ukrainian Association of Nephrology (affiliated by the International Society of Nephrology).

**Prof. Dr. Z. Serhan Tuğlular**
***Chair, Renal Disaster Relief Task Force of the European Renal Association***

Prof. Dr. Tuğlular graduated from Istanbul University School of Medicine in 1986, completed her residency in Internal Medicine in 1996 and fellowship in Nephrology in 1999 at Marmara University School of Medicine. She is a former International Society of Nephrology Fellow. She has a special interest in renal transplantation and renal vasculitis. Has been appointed as the chair of Renal Disaster Task Force of the Turkish Society of Nephrology in 2018 and has been coordinating the activities of the nephrology community during the last earthquake of south-eastern Turkey. She has also been involved in educational activities for the treatment of Crush Syndrome in various regions of Turkey since 1999. Dr Tuğlular was appointed as the chair of Renal Disaster Relief Task Force of the European Renal Association, started soon after the war in Ukraine in February 2022. She is a member of the Turkish Society of Nephrology, European Society of Nephrology and International Society of Nephrology. In addition to her clinical activities, she has published numerous articles in international journals and she is a member of the editorial board of the Turkish Journal of Nephrology.

**Prof. Em. Raymond Vanholder**
***President, European Kidney Health Alliance***

Prof. Em. Vanholder published more than 900 papers, including reviews and book chapters, on adequacy of dialysis, uremic toxicity and various topics related to clinical nephrology. He serves as a member of the editorial review board of several journals and is subject editor of Nephrology Dialysis and Transplantation and Toxins. Up till autumn 2010, he was chairman of the European Uremic Toxin Work Group and member of the Executive Board and treasurer of Kidney Disease Improving Global Outcomes. Up till summer 2011 he was chairman of the European Renal Best Practice. Up till autumn 2014, he chaired the Renal Disaster Relief Task Force of the International Society of Nephrology and participated in several international relief operations. Prof. Em. Vanholder was founding president of the Belgian Society of Nephrology, is past president of the European Society of Artificial Organs and immediate past president of the European Renal Association. He is now retired (Prof. Em. at Ghent University) and chair of the European Kidney Health Alliance and of the European Chronic Disease Alliance.