

Nephrology Nomenclature: How to Accelerate Patient Anxiety, Suppress Engagement, and Mire the Advance of Medical Innovation

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As a Patient Editor for *CJASN*, I have been extended several important privileges. First, of course, is continuous exposure to the rich and diverse range of research and scholarly writing from experts across the entire continuum of kidney diseases and kidney research. Second is the ability to recommend fellow patients with kidney disease who may be interested in offering their viewpoints on particularly timely submissions in their roles as either or both patients and professionals to the *CJASN* editorial team. Third, I have the rare opportunity to elevate articles to *CJASN* readers that, as a patient and professional practitioner of both public policy and political communications strategy, I believe have deep implications for patients, the nephrology profession, and our shared fight for more resources for research and innovation.

I would recommend that every *CJASN* reader read the article “Patient and Caregiver Perspectives on Terms Used to Describe Kidney Health” (1). Tong (of the Sydney School of Public Health at the University of Sydney) and colleagues (1) have documented, through their research, one of the sad and often infuriating truths that nearly every patient with kidney disease or caregiver has felt, believed, or experienced at some point in the battle with kidney disease. Stated simply, nephrology nomenclature was designed by professionals to make sense within the highly narrow silo of kidney medicine and kidney research and primarily among other kidney professionals. As communicated to patients, this insular nomenclature is rarely well understood and typically misunderstood. Additionally, if not deciphered in a meaningful and relatable way to patients, nephrologists may, unwittingly, be exacerbating the worst fears of morbidity and feelings of hopelessness within their patients. At the minimum, much of the terminology used by kidney professionals creates barriers to patients’ understanding of their disease, their current and future prognoses, and their sense of ownership and/or confidence to be involved in their own care.

The findings may be tough for some professionals to grasp or to accept—but the time is now to be honest and accept the insights of patients, as researched and documented by peers. Optimistically, the article

provides multiple practical recommendations that professionals could adopt immediately in their conversations with their patients and across all care settings. Ideally, curriculum enhancements or Continuing Medical Education credits for breaking barriers posed by nephrology nomenclature (and increasing patient engagement in their own health outcomes) would include both “Patient and Caregiver Perspectives on Terms Used to Describe Kidney Health” (1) and the straightforward article “12 Tips to Nephrology Teams Supporting Patients with Advanced Kidney Disease: An Advocate’s Dozen” authored by Hickey (2), which appeared in the June 2018 edition of *CJASN*, as mandatory reading for every kidney professional who interacts with a patient—regardless of title or position.

As a kidney community, we are living in an era of remarkable and long-overdue attention to kidney diseases among a full range of top influencers who have both the authority and power to reprioritize public and government attention and realign investments to fight kidney diseases. These include the Trump Administration (which issued the Executive Order on Advancing American Kidney Health in July of 2019); bipartisan leaders in the US Congress and the US Senate; and key investors and private sector executives in companies entering the race to develop new diagnostics, biologics, and devices in the kidney space. Combined with the influence and results already being demonstrated by the Kidney Health Initiative, the Kidney Precision Medicine Project, and the KidneyX prize competition, new advancements in kidney research and innovation are indeed happening, and knowledge of our advances is growing among the mainstream media and across the general public.

However, the achievement of long-term and sustainable victories in the fight against kidney diseases must not be left to top influencers—for their attention span is notoriously short and their agendas are subject to political and market volatility. Instead, the nephrology community must do a better job of incorporating one of the most powerful voices and assets it has—the broader-based and extremely diverse

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patient community that it serves. However, to enlist patients more fully, professionals must place greater thought in how they communicate with patients about kidney diseases and the specific language they use. If our shared agenda is to have more patients participate in clinical trials and research, take better care of themselves, and become more involved in advancing policies that support innovation and research—ask yourself a simple question: did the last conversation I had with a patient inspire confidence that his or her kidney disease is manageable and that his or her unique patient insights are valuable and needed in the fight to help save other patients? If your answer is yes, you are to be commended. However, if your answer is no, please read both “Patient and Caregiver Perspectives on Terms Used to Describe Kidney Health” (1) and “12 Tips to Nephrology Teams Supporting Patients with Advanced Kidney Disease: An Advocate’s Dozen” (2) and start making a more positive effect on patients and the nephrology profession as you go forward in your career.

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