

# Patients have an important voice in shaping kidney disease research and treatment

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In an effort to provide patients the opportunity to share practical health consumer perspectives, the *Clinical Journal of the American Society of Nephrology* (CJASN) is including Patient Voice editorials that will accompany certain journal articles. In the first editorial, Paul T. Conway, a past recipient of the ASN President's medal, highlights 2 CJASN articles that focus on patient comprehension of how treatments align with their individual interests.

Conway has extensive experience both as a patient who has managed kidney disease for more than 36 years and as a policy practitioner who managed policy implementation in senior roles under 4 US presidents.

In the first article that Conway highlights, New Zealand [patients](#) with [chronic kidney disease](#) who prefer home dialysis do so based on their understanding of flexibility, comparative independence and potential for better survival. "Time will tell if doctors and providers, presently the most influential forces shaping patient treatment choices, work more closely with their patients to align treatment choices to patient aspirations, including the pursuit of meaningful work and careers," wrote Conway.

The second article, involving patients in China, highlights the lower brain function in patients with end-stage [kidney disease](#) even when treated with dialysis, as well as how transplantation is associated with improvements in many aspects of brain function. "If patients eligible for transplantation knew the potential impact of transplantation on mental

function compared to dialysis, including the capacity to more fully assume family obligations and career pursuits once forfeited to disability, I believe the number of patients electing transplantation, including pre-emptive transplants, would markedly increase," Conway stated.

Conway notes that increasingly, patients are being respected as intelligent consumers of healthcare with valuable insights and experiences, and they're being included at every step in the development and approval of devices, diagnostics, and biologics.

"Both CJASN and the American Society of Nephrology, through very well-defined strategies and practical efforts, are educating the public, Federal policy-makers, and kidney professionals on how the inclusion of the patient voice drives innovation and improves individual health outcomes," he said. "Their shared sense of urgency on behalf of [kidney patients](#) and bias for action, in the eyes of the advocacy community and across the corridors of influence in Washington D.C., stand in stark contrast to other well-intentioned efforts that will likely never evolve from research to timely application designed to benefit patients."

In an editorial highlighting "what's behind and what's ahead" for CJASN, the journal's editors note that the truest measure of value for every paper they publish is its ultimate impact on patient care. Concerning the Patient Voice editorials, they "hope that these perspectives will provide valuable feedback to clinicians and researchers on the importance and limitations of Nephrology research and what more needs to be done."

**More information:** The editorials, entitled "Trust Patient Insights at Both the Individual and National Level" and "CJASN: What's Behind and What's Ahead," will appear online at [cjasn.asnjournals.org/](http://cjasn.asnjournals.org/) on December 21, 2017.

The accompanying articles, entitled "A Discrete Choice Study of Patient Preferences for Dialysis Modalities" and "Re-Establishing Brain Networks in Patients with ESRD after Successful Kidney Transplantation," are currently online at [cjasn.asnjournals.org](https://cjasn.asnjournals.org).

Provided by American Society of Nephrology

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