

## Summary of Kidney Disease Advocacy Study

We studied kidney disease advocacy among dialysis patients. We defined **kidney disease advocacy as the act of speaking out on behalf of persons with kidney disease or on behalf of a kidney disease-related cause.** The main goals of the study were to better understand what dialysis patients think about advocacy and to learn the main challenges to participating in advocacy.

We interviewed **48 dialysis patients** to learn about their views. The patients were from **14 states**. Their average age was 54 years and about half were female. About half had participated in advocacy activities at the state or national level.

We learned a lot from our study. Patients generally understood the concept of advocacy, but many were unaware of how to get involved in advocacy in their local area. Patients offered several reasons for why they don't participate in advocacy, including limited time, poor health and limited transportation. Among those who participated in advocacy activities, key reasons for getting involved included a desire to help others and an interest in personal education.

The dialysis patients we interviewed believed the following about how to help increase kidney disease advocacy:

- **Face-to-face invitations** for advocacy activities **delivered by other patients** are the most effective form of communication.
- **Social events** with food and educational presentations are helpful.
- **Involve patients** in the design and development of advocacy education programs.
- Most of the patients believed they had the ability to participate in advocacy **but had never been asked to participate.**

***One patient said: "I think I would let the patients help design it [an advocacy education program].... I think it might be a different answer for every center."***

**Summary: There is great potential for increasing advocacy in the kidney community. We believe all patients can participate in some way.**

***Interested in getting involved in advocacy? Ask your dialysis social worker or doctor. Kidney-related advocacy groups include: National Kidney Foundation, American Association of Kidney Patients, Renal Support Network, Dialysis Patient Citizens, Home Dialyzors United, Nephcure, Alport Syndrome Foundation and Vasculitis Foundation***

***From:*** "Dialysis patient perspectives on kidney disease advocacy: a semi-structured interview study. Published in the American Journal of Kidney Diseases on August 20, 2016. By: Gregory Schober, Julia Wenger, Celeste Lee, Jon Oberlander and Jenny Flythe.