



May 8th, 2015

The Honorable Tom Cole
Chairman
Committee on Appropriations
Subcommittee on Health
2358-B Rayburn House Office Building
Washington, D.C. 20515

The Honorable Rosa DeLauro
Ranking Member
Committee on Appropriations
Subcommittee on Health
2358-B Rayburn House Office Building
Washington, D.C. 20515

Re: Inclusion of Home Dialysis in AHRQ Committee Report Directions

Dear Chairman Cole and Ranking Member DeLauro:

The Alliance for Home Dialysis (Alliance) appreciates the Committee's investment in medical research that fosters the development of new technologies for patient benefit. Unfortunately, some patients do not currently have access to technologies that could enhance the quality of their medical care. As the Committee reevaluates its national investments in research, the Alliance urges you to invest in the identification of barriers to access to a critical treatment option: dialysis treatment in the home.

The Alliance is a coalition of kidney dialysis stakeholders representing patients, clinicians, providers, and industry. We have come together to promote activities and policies that facilitate treatment choice in dialysis care while addressing systemic barriers limiting access for patients and their families to the many benefits of home dialysis.

Accordingly, the Alliance encourages the Committee to include a recommendation in its final report on FY2016 funding for Labor, Health and Human Services, Education, and Related Agencies directing the Agency for Healthcare Research and Quality (AHRQ) to explore the barriers that patients face when making choices about whether or not to dialyze at home. Research suggests that between forty and fifty percent of patients choose home dialysis when fully-educated about their options. However, less than twenty percent¹ of new patients entering dialysis ultimately end up in the home.² This disconnect between patient preferences and real-life outcomes suggests pervasive systemic barriers to patient choice, including but not limited to billing practices surrounding the frequency of treatments, insufficient education for patients and physicians as to who might benefit from home treatment, and others.

¹ United States Renal Data System, 2014 Annual Data Report: Epidemiology of Kidney Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2014.

² See, Golper, Thomas, and Saxena A. "American Journal of Kidney Diseases." Systematic Barriers to the Effective Delivery of Home Dialysis in the United States: A Report From the Public Policy/Advocacy Committee of the North American Chapter of the International Society for Peritoneal Dialysis. 58.6 (2011): 879-885. Web. 16 Jul.

Specifically we encourage the Committee to adopt the following language, recommended by Congresswoman Robyal-Allard:

Patients who dialyze at home account for only about 10 percent of all patients with ESRD. While there is a growing body of literature that home dialysis may result in better clinical and quality of life outcomes for some patients, adoption in the United States is relatively limited compared to similar countries. Challenges may include limited awareness of home dialysis options among dialysis patients, the complexity of training, and the need to perform self-care or have a trained care partner. Moreover, there are significant racial disparities in home dialysis utilization; racial/ethnic minorities are substantially less likely to dialyze at home than Caucasians.

The Committee therefore encourages AHRQ to provide funding for identifying mechanisms to help overcome educational, economic, and other barriers to home dialysis among patients with ESRD, particularly among racial/ethnic minority populations.

AHRQ is uniquely positioned to examine the clinical and economic constraints patients and providers face in ensuring that patients who are well-suited for home dialysis receive their preferred treatment. While previous studies have examined the correlation between home dialysis and various health benefits³, the Alliance believes that a holistic investigation into educational, economic, and other hurdles could provide insight into how ESRD reimbursement could more effectively promote patient choice. As an agency with a wide range of expertise, AHRQ can examine the clinical, educational, and economic factors that affect patient choice, and promote comprehensive, evidence-based research that will benefit policymakers, clinicians, and patients alike.

The Alliance appreciates Congresswoman Roybal-Allard's leadership in preparing comments that would direct AHRQ to focus on this important issue. We agree with the Congresswoman that the availability of home dialysis promotes choice and allows patients to plan their treatment in a way that provides independence and flexibility. Further investigation into any barriers in the current system will only serve to promote patient choice.

The Alliance is happy to serve as a resource for the Committee during your FY2016 appropriations process, and is happy to answer any questions you may have about home dialysis or patient access generally. Please direct any questions to me at (202) 466-8700 or ebrooks@homedialysisalliance.org.

Sincerely,

Elizabeth Brooks

Elizabeth Brooks
Director of Policy

Cc: Chairman Harold Rodgers and Ranking Member Nita Lowey

³ See, e.g., Blagg, Christopher. "It's Time to Look at Home Hemodialysis in a New Light." Hemodialysis Horizons: Patient Safety & Approaches to Reducing Errors. (2006): 22-28. Web. 12 Apr 2012
<http://www.aami.org/publications/HH/Home.Blagg.pdf>.



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