

August 31, 2011

Ms. Cheryl C. Ulmer  
Study Director, Determination of Essential Benefits  
Institute of Medicine of the National Academies  
Keck Center, 765  
500 Fifth Street NW  
Washington, DC 20001

Re: Determination of Essential Benefits in the Health Insurance Exchanges

Dear Ms. Ulmer:

On behalf of Dialysis Patient Citizens (DPC), a national, non-profit organization with a membership of more than 23,000 dialysis and pre-dialysis patients and their family members, I am writing to urge the Institute of Medicine (IOM) to include both dialysis and transplantation in the essential benefits package it recommends the Department of Health and Human Services (HHS) adopt for the new health insurance exchanges. With more than 31 million Americans suffering from chronic kidney disease (CKD), it is critical for patients to have access to kidney treatments, especially dialysis and transplants.

Each year in the United States, more than 100,000 Americans are diagnosed with end stage renal disease (ESRD), an irreversible condition which is fatal without a kidney transplant or lifesaving dialysis treatments. Currently, more than 485,000 Americans suffer from ESRD and 341,000 are on dialysis, a number that is expected to double over the next decade. This dramatic rise is attributable to the increased prevalence of diabetes and hypertension, two skyrocketing chronic diseases and the leading risk factors for ESRD.

When defining essential benefits for the health exchange plans, we find it difficult to imagine the exclusion of dialysis and transplantation, as both are absolutely essential to the survival of an ESRD patient. In fact, these life-preserving treatments allow hundreds of thousands of Americans to live high quality and fulfilling lives. Mandating dialysis as an essential benefit will enable thousands of Americans to take advantage of new coverage opportunities the exchanges create.

We also urge IOM to consider the possibility of dialysis coverage limits in their essential benefit analysis. Individuals who have or develop ESRD should not be subject to benefit designs that limit their coverage to lifesaving therapy, such as dialysis. We would like to see protections included to ensure plans are unable to limit coverage to a defined number of treatments or a defined period of time. Such "de facto" annual/lifetime limits should be prohibited for all plans, whether inside exchanges or not.

As America's largest dialysis patient organization, we are committed to improving the quality of life for all dialysis and pre-dialysis patients by engaging policy makers, providers and the public. Through patient education, empowerment and advocacy, we work to increase awareness about the unique needs of this patient population. As a result, DPC appreciates the opportunity to weigh in on this important issue and we hope that IOM will fully consider the needs of kidney failure patients when presenting their recommendations to HHS.

Sincerely,

A handwritten signature in black ink, appearing to read "Hrant Jamgochian". The signature is fluid and cursive, with the first name "Hrant" being more prominent and the last name "Jamgochian" following in a similar style.

Hrant Jamgochian  
Executive Director