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Re: Essential Health Benefits (EHB) Under Section 1302 of the Affordable Care Act

January 31, 2012

Home Dialyzors United (formerly NxStageUsers) is a 501(c)(3) nonprofit organization whose mission is to support home dialysis patients with chronic kidney failure, also known as End Stage Renal Disease, and to advocate for optimal treatment and rehabilitation. In slightly over four years, Home Dialyzors United (HDU) has grown into the largest patient and care partner organization dedicated to home dialysis. On behalf of those members, we are writing to comment on the Essential Health Benefits portion of the Patient Protection and Affordable Care Act.

We feel that Home Dialyzors United is eminently qualified to comment and to offer expertise because our members live with the reality of chronic kidney failure every single day.

First and foremost, dialysis or transplantation is inherently essential to sustain the lives of over one half million people with chronic kidney failure and must therefore be included in the essential benefits package. Without these renal replacement therapies, the only outcome for these patients is death.

Due to the necessity of dialysis and dialysis related services being included in the essential benefits package, we will comment on several of the benefit categories individually.

Ambulatory patient services

The vast majority of chronic kidney failure patients (approximately 91%) dialyze in outpatient centers and the services to those patients must be protected. However, an increasing number of people choose to dialyze at home and this modality must also be considered ambulatory services.

Emergency services

Due to the complexities inherent in treating chronic kidney failure, dialyzors must, on occasion, depend on the services of the hospital emergency department. Those who dialyze more often and/or for extended time are less likely to need emergency interventions and thereby will incur less of a financial burden on any reimbursement system. Research has shown that those who

dialyze for a minimum of 3 ½ -4 hours, three days per week are frequent users of emergency services, especially after two days without treatment, which is often called the “killer weekend.”¹

Hospitalization

Hospitalization rates for dialysis patients, especially those who treat in-center, are presently far too high with estimates that 36% of yearly costs are due to hospitalization. Keeping dialysis patients healthy and out of the hospital should be another priority of any benefit package. All home modalities, including more frequent and extended time, should be a mandatory part of the essential benefits package. The cost of hospitalization is enormous when compared to the cost of more frequent or extended time dialysis.

The January 13, 2011, report to the Institute of Medicine, Committee on the Determination of Essential Health Benefits, by America's Health Insurance Plans states “...we believe that Congress has already specified an appropriate set of 'essential' items or services that should be included in the essential health benefits package and there should be no further defining of specific service elements of the benefit package, such as the number or frequency of services that should be covered.” We strongly disagree!

In the case of chronic kidney failure, the recent Frequent Hemodialysis Network (FHN) study, sponsored by the National Institute of Health and the Centers for Medicare and Medicaid Services, clearly shows the advantage of more frequent dialysis. To allow qualified health plans to exclude this modality would have a negative impact financially as well as on patients' physical and psychosocial well being. Decisions regarding optimal treatment should be left to the physician and patient and not be arbitrarily limited.

Mental health and substance use disorder services, including behavioral health treatment

Research has shown that depression in dialysis patients is an independent predictor of mortality and should therefore be included for all patients, regardless of primary diagnosis.

Prescription drugs

Laboratory services

In the recently implemented Prospective Payment System for dialysis services, some drugs and laboratory services directly related to dialysis treatment are included in the bundle. Those drugs and laboratory services excluded from the bundle should be available to dialyzors in the essential benefits package.

¹Foley, Robert et al., “Long Interdialytic Interval and Mortality Among Patients Receiving Hemodialysis,” NEJM 2011; 365: 1099-1107

Rehabilitative and habilitative services and devices

The original intent of the Medicare ESRD program was to enable patients to remain productive and employed. Unfortunately, today, 79% of dialysis patients, age 18-54, are unemployed. What began as a rehabilitation focused program has instead fostered debilitation and forced disability. With the rise of large dialysis companies, profit has often taken precedence over patient need and goals.

In order to restore the rehabilitation intent of the law, we would also recommend 1) the Medicare ESRD program be redefined as a renal rehabilitation program 2) a national, defined, coordinated renal rehabilitation agenda be implemented, incorporating the best existing ideas 3) implementation of a GAO study on the economic impact of renal disability and 4) use of employment statistics as one measure of quality care.

Preventative and wellness services and chronic disease management

There is no other condition quite like chronic kidney disease. Especially in stage 5 (chronic renal failure), it affects every aspect of a patient's and his family's life 365 days a year. Considering this reality, prevention, early detection and slowing progression is of the utmost importance. For those with chronic kidney failure, preventing complications is the key to remaining healthy with dialysis.

Chronic kidney disease has reached epidemic proportions largely due to the alarming increase in diabetes, high blood pressure and obesity. Without timely and coordinated intervention, the incidence of chronic kidney failure will continue on its upward trajectory. We urge inclusion of preventative measures including, but not limited to, patient education in the essential benefits.

In addition to our comments above, we would also stress that dialyzors must have choice and access to the modality of choice even if the modality is not offered by the payers preferred provider. This choice must also extend to the time or shift best suited to accommodate the patient's continued employment.

Furthermore, the Center for Consumer Information and Insurance Oversight has suggested that the following four benchmark plan types for 2014 and 2015 best reflect the statutory standards for EHB in the Affordable Care Act:

1. the largest plan by enrollment in any of the three largest small group insurance products in the State's small group market;²⁶
2. any of the largest three State employee health benefit plans by enrollment;
3. any of the largest three national FEHBP plan options by enrollment; or
4. the largest insured commercial non-Medicaid Health Maintenance Organization (HMO) operating in the State.

We are concerned of the possibility our members will lose their preferred method of treatment because many of the predicate plans have policies which state the type of portable dialysis machine

our members use is considered experimental and investigational, albeit approved for usage by the U.S. Food and Drug Administration.

We understand that the essential benefits package is to be “based on credible and appropriate scientific evidence.” While we totally agree with this aspect of the law and our comments conform to this standard, we also believe that observational and anecdotal evidence must not be ignored. Patients whose lives and well being depend on your decisions deserve to be heard.

Home Dialyzors United appreciates the difficulty of the task ahead. We appreciate the opportunity to comment on the essential benefits package and would be pleased to provide further input into the discussion.

Sincerely,



Richard J. Berkowitz
Founder and President



Denise Eilers, RN, BSN
Chair, Public Advocacy Committee