

## Renal Support Network Testimony

My name is Kathe LeBeau. I have been a home hemodialysis patient for almost three years now and a patient advocate working with the Renal Support Network, an organization for people with kidney disease that is run by patient for patients. To help gather and bring the concerns of informed patients to this meeting, RSN created a discussion board where patients and family members could weigh in, ask questions and express their thoughts about the Proposed Rule, providing a microcosm snapshot of patients' reaction to the bundle. We have also hosted more than 20 conference calls with patients to discuss aspects of the Proposed Rule and held a three day patient summit on bundling

### **1- Unit of payment**

Patients are grateful for both the decision to continue to reimburse on a per treatment basis and to include the provision for medically justifiable additional treatments. As a home patient, I have seen the difference that **more frequent treatments** can make to patients who were barely surviving before on a 3x/week standard treatment regimen.

### **2-Lab**

Patients do have concerns about many components of the Proposed Rule, especially those patients who are medically more complicated, or who require a greater number of routine lab tests and more expensive medications to maintain their health status. The treatment of kidney disease through renal replacement therapy is a very delicate balance and often requires repeated tests to be certain that potassium, calcium, phosphorus, and hemoglobin are all within range, as the consequences of them being too high or too low are often deadly. We are not aware of **any minimum standards** that are set on how often or when labs should be drawn. Some tests are expensive and we question if the proposed bundled amount of \$9 per treatment is enough to safely monitor the patient. If the bundled payment is not adequately reimbursed won't providers be more reluctant to perform these tests as often as may be necessary? Also, a specified list needs to be created of ESRD lab tests, so there is no confusion. For example, we would hope that labs for transplant evaluation would be excluded from the bundle.

### **3-Medications**

The same holds true for oral medications that are proposed to be included in the bundle.

We understand that the proposed bundled payment includes \$14.00 per treatment for oral medications. That's \$182.00 per month. It simply doesn't compute, with patients taking an average of 10 different oral medications per day, that this will be sufficient to cover the cost.

Also, it is possible that cost shifting could occur to avoid the use of more expensive drug treatments. We are concerned that we will return to earlier clinical standards when patients were sent to surgery to remove their parathyroid glands or to the hospital to receive a blood transfusion.

We therefore ask what safe guards will be put in place to ensure that Nephrologists will continue to be able to order the necessary medications to provide appropriate care for people on dialysis.

#### **4-Quality Measures**

A further concern of patients is the safety and quality of their care. While we appreciate the opportunity to have input into the quality measures as they are being developed and implemented for a subsequent proposed rule, it is concerning that the current proposed rule will be implemented with only two quality indicators, anemia and adequacy.

What will measure quality fully in the meantime? Patients worry about the process by which they will have safeguards for their care if a more robust quality program is not implemented until a year after the institution of bundling.

And while we understand the lengthy process involved in collecting data for measures to be determined as quality indicators, two anemia and a dialysis adequacy measure seem insufficient and do not equally reflect the quality of treatments across all modalities.

We would encourage the inclusion of additional quality measures such as bone and mineral metabolism management, hospitalizations, infection rates, work/rehab measures and a process measure of patient's satisfaction with treatment. This would give a more comprehensive picture of the quality of treatment provided.

#### **5-Co-pays**

Another concern is how this will affect the co-pays for patients. Lab tests currently have NO co-payments and oral medications under Medicare Part D are covered by a number of different insurance and supplemental plans that require little or no co-payments. Under the proposed rule, a relatively healthy patient with no co-morbidities and no outlier payments would now have a co-pay of \$46.30 per treatment. That's approximately \$7,223.00 per year.

### **6-First 120 days**

We are pleased that you recognized the increase in payment of 47% for the first 120 days of dialysis because this is such a difficult transition time for people who start dialysis. But we want to point out that people who are not yet 65 do not become eligible for Medicare until the 90 days coordination period expires. This only allows them 30 days of increased payment, not 120.

### **7-Training Payment**

Patients are also concerned about the inclusion of training costs within the bundle and believe that there should be a separate payment for home training. Training for home dialysis can occur at different times after a patient starts dialysis. We believe the extra payment should be linked to the training and not the time on dialysis.

In conclusion, I would like to remind everyone involved that if we do not get this right - patients pay with their lives. These patients are our friends, family members and colleagues. They could be you or your friends and loved ones. They are people exactly like me.

I thank you for your time and for this opportunity.