American Kidney Fund 6110 Executive Boulevard Suite 1010 Rockville, Maryland 20852

301.881.3052 voice 301.881.0898 fax 800.638.8299 toll-free 866.300.2900 Español www.kidneyfund.org Member: CFC 0508



October 30, 2007

The Honorable Max Baucus Chairman Committee on Finance United States Senate Washington, DC 20510

Dear Chairman Baucus:

As the Finance Committee considers important Medicare legislation, I am writing to share the American Kidney Fund's views on changes to the Medicare End Stage Renal Disease (ESRD) Program.

For more than thirty five years, the American Kidney Fund's mission has been to reduce the enormous financial burden confronting Americans, and their families, suffering from ESRD, and to enhance awareness of kidney disease. As the incidence of ESRD has grown, the scope of our assistance has multiplied. Last year we provided \$81.9 million in grant assistance to more than 63,500 ESRD patients nationwide to pay for treatment-related essentials. Our grants help patients maintain health insurance coverage and pay for other necessities that insurance typically does not cover such as medication and transportation related expenses. We believe that our work with vulnerable kidney disease patients and their families provides us with a perspective and insight that are useful in the examination of these issues. Our experience also enhances our commitment to reduce the number of families touched by this illness.

The American Kidney Fund hopes that you will include a number of positive changes to the ESRD Program designed to raise awareness of kidney disease, educate patients and their families about treatment options, and improve the quality of care. Specifically, we support strongly the Chronic Kidney Disease Demonstration Projects, approved by the House of Representatives earlier this year in the CHAMP Act, designed to raise public awareness about kidney disease. We believe that the number of demonstration projects should be increased and the eligibility expanded to include not for profit national kidney disease organizations with experienced, effective and targeted chronic kidney disease screening programs.

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We also support provisions included in the House-passed bill to teach self management and prevention skills; educate people with kidney disease to slow the progression and make informed treatment choices; evaluate the barriers to home dialysis; establish uniform training of dialysis technicians; and create incentives for continuous quality improvement in dialysis care.

The quality of care delivered to patients is impacted by the financial health of the provider community and we support a statutory mechanism for assuring that the reimbursement rate for dialysis providers keeps pace with changes in costs. Dialysis has the dubious distinction of being the only Medicare prospective payment system without an annual update mechanism. This fact has resulted in irregular and insufficient adjustments that have squeezed the industry and forced a number of smaller, independent providers out of business, adversely affecting access for many dialysis patients.

We understand the difficult budgetary challenges you and your colleagues face and recognize that new spending must be offset by cuts in other areas. We support an additional 12 month extension of Medicare secondary payer (MSP) as a means to generate savings to help offset the costs of other improvements for patients in the ESRD Program.

We want to thank you for your long record of leadership in improving health care benefits and services and urge you to adopt changes to the ESRD program that will expand awareness and improve care.

Sincerely,

LaVarne Burton

Chief Executive Officer

cc: Finance Committee Members



October 22, 2007

The Honorable Max Baucus Chairman, Senate Finance Committee 511 Hart Senate Office Building Washington, D.C. 20510

Dear Senator Baucus,

As America's largest dialysis patient organization, DaVita Patient Citizens (DPC) is proud to represent over 20,000 pre-dialysis and dialysis patients and their families. On a wide variety of issues, we seek to ensure that the patients' point of view is heard and considered by policy makers so that continued progress may be made in the quality of care and life for patients with kidney disease.

On Capitol Hill recently, an organization called the American Association of Kidney Patients (AAKP) asserted that all kidney patients oppose the extension of the Medicare Secondary Payer (MSP) from 30-42 months. Representing over 20,000 patients, DPC takes issue with AAKP's assertion. In fact, DPC advocates for extending the MSP from 30-42 months as a key part of the larger goal of improving kidney care for our nations 330,000 End Stage Renal Disease (ESRD) patients and the more than 20 million Chronic Kidney Disease (CKD) patients. Further, this reform is advocated by Kidney Care Partners, a coalition of thirty-two patient, provider and supplier organizations representing the broader kidney community.

Currently ESRD is the only disease condition where private insurers can limit coverage. Even if patients want to remain in their private health insurance plan, they are forced after 30 months to go onto Medicare. Often this means that patients and their families are confronted with higher out-of-pocket costs, less comprehensive health coverage, and much greater complexity as they try to navigate Medicare (for the patient) and private insurance (for their family).

As the wife of one of our members told us, "We feel we deserve the right to choose and not be forced into Medicare so early, undercutting our current plan. It is only fair that we continue to at least have the choice of staying with our plan for a bit longer." Extending MSP would allow patients and family members to continue to maintain their health insurance longer before they are pushed onto Medicare.

Besides restricting patients' right to choose to keep their private insurance coverage longer, not extending the MSP period will prevent many of the needed reforms within the ESRD program. One of the most important steps is to provide those individuals at risk of kidney failure with education about the factors associated with kidney disease in the hopes of preventing them from



reaching kidney failure. Consistently our members state that they were not aware of the risk factors that cause much of kidney disease—diabetes and hypertension. Prior knowledge could have reduced their risk of kidney failure and possibly dialysis, and the savings that MSP extension would achieve will help fund much-needed education and prevention programs.

Before Congress's foresight in 1972, only those who had personal resources were able to receive dialysis, and thus live. Medicare was created as a safety net to help those who could not afford to pay for dialysis' life saving treatments. With the MSP extension, the Medicare safety net remains intact and the potential exists to provide additional benefits to patients—pre-dialysis education, continuity of care, and CKD prevention.

As America's largest dialysis patient organization we hope that this modest extension in MSP is approved and that the savings are used to help educate others about kidney failure and to improve the quality of life for all dialysis patients. We urge Congress to continue to provide the leadership and means that allow our nation's dialysis patients to receive high quality care.

Sincerely,

Chad Lennox

**Executive Director** 



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October 31, 2007

The Honorable Max Baucus Chairman Committee on Finance U.S. Senate Washington, DC 20510

The Honorable Charles Grassley Ranking Member Committee on Finance U.S. Senate Washington, DC 20510

#### Dear Senators Baucus and Grassley:

On behalf of the 20 million Americans with chronic kidney disease (CKD), including nearly 350,000 dialysis patients, the National Kidney Foundation respectively requests that any Medicare legislation considered by the Senate include improvements to the Medicare end stage renal disease (ESRD) program.

H.R. 3162, the Children's Health and Medicare Protection Act (CHAMP), as passed by the House, contained enhanced benefits for kidney patients. NKF understands the need for an offset in the current Pay-Go environment. Therefore, we reiterate NKF's longstanding decision to support extension of Medicare Secondary Payer, to 42 months, as proposed by the House, provided that the savings are dedicated to improvements to the Medicare ESRD program.

Of particular interest to NKF is Medicare coverage of educational sessions for beneficiaries with Stage 4 chronic kidney disease, to provide information on various options of renal replacement therapy, including modalities of dialysis and the possibility of kidney transplantation as well as information about the management of the additional medical conditions that accompany chronic kidney disease. However, the CHAMP Act does not authorize Medicare payment to dietitians and social workers for predialysis education services. We prefer the parallel provision in the free standing predialysis education bills in the Senate and House (S 432 and

HR 1245) and in the Kidney Care Quality and Education Act (S 691 and HR 1193). These professionals are an important part of the CKD health care team and we believe they should be eligible to bill Medicare for these services. We also support provisions that would establish demonstration projects to increase CKD awareness, surveillance and research and a provision that dialysis technicians be certified within 12 months after training. We also believe the study required in HR 3162 on possible barriers to broader utilization of home dialysis therapies should be included in the Senate Medicare package.

Thank you for your consideration.

Sincerely,

John Davis, CEO

cc: Senate Finance Committee Members



#### Service to those affected by chronic kidney disease

October 30, 2007

Lori Hartwell Executive Director/President

Jacki Harris, RN Chairman of the Board

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Board Members: Rhonda Brooks Sara Colman, RD Jeffrey Davis Stephen Furst Jacki Harris, RN Lori Hartwell Kerri Jacobson Lana Kacherova, RN Malia Langen Sandra Wilson, RN The Honorable Debbie Stabenow United States Senate 133 Hart Senate Office Building Washington, DC 20510

Dear Senator Stabenow:

Re: Extending MSP to 42 Months

I am the founder and president of the Renal Support Network (RSN), a nonprofit organization of kidney patients that is dedicated to improving the lives of people with kidney disease. I am writing to provide you with a different perspective on the Medicare Secondary Payer (MSP) period, and to ask you to support the 42-month MSP (with a few vital revisions).

I am aware of the statement made by the American Association of Kidney Patients (AAKP) at the briefing last week when they opposed the CHAMP provision that would extend the MSP period for ESRD beneficiaries from 30 to 42 months. We at the RSN take issue with AAKP's statement that they are THE singular voice of kidney patients, and would like to provide you with a different patient perspective that reflects the opinion of our patient members. There are several facts that we would like you to consider when evaluating how extending the MSP to 42 months may positively benefit patients:

- Under current MSP policy, dialysis patients are *required* to switch from their employer-sponsored private health insurance and become primary Medicare beneficiaries after 30 months of Medicare entitlement. This requirement limits patient choice and may result in changes in the quality of care that they receive.
- O AAKP's statement made it sound as if Medicare is the best possible insurance policy. This is simply not the case. Private health plans are starting to employ many tools, such as case managers, to improve outcomes and reduce the costs of the complex care kidney patients require. Many patients would like to stay on their private health insurance

An illness is too demanding when you don't have hope!

# Renal Support Network

longer because, compared with Medicare, they receive more comprehensive coverage and often have lower out-of-pocket costs.

- O Patients on dialysis can currently enter Medicare at any time during the 30-month period if they drop their private insurance. However, some patients choose not to exercise this option because: (a) it may result in the loss of disease management services and other benefits that are provided by their private health plan but not by Medicare, and (b) their dependent family members may lose their health insurance. (Note that some patients do choose to switch to Medicare as their primary payer when they become eligible after the third month of ESRD—but the choice is theirs and can be based on their personal circumstances.)
- o The CHAMP MSP extension would be the fourth such extension made by Congress. The provision gives dialysis patients *the right to choose* whether to stay privately insured for up to 42 months. Importantly, the CHAMP proposal only applies to employer-sponsored plans with more than 100 enrollees.
- People who oppose the MSP extension say it would create a burden on employers and the private insurance plans they sponsor. However, based on the real experience of a large group of patients, it has been estimated that the MSP extension would have negligible-to-no impact on health insurance premiums. Only a small fraction of the total 341,319 Medicare beneficiaries on dialysis fall within the population that would be affected by the additional 12 months of the Medicare Secondary Payer provision.
- O By keeping Medicare beneficiaries on their employer-sponsored plans for a longer period, the MSP extension helps beneficiaries decrease their exposure to potentially high co-payments that they would otherwise experience under Medicare. (They are protected from high co-payments while in the MSP period due to the fact that their private insurance generally pays rates higher than Medicare and, if it does not, Medicare pays the difference up to what Medicare would otherwise have paid.) The law prevents balance billing of Medicare beneficiaries in these circumstances. In addition, any primary payments from a third-party payer for Medicare-covered services are credited toward the beneficiary's Medicare Part A and Part B deductibles and, if applicable, coinsurance amounts.

AAKP did express some concerns shared by the RSN members I have spoken to about this subject, and we believe that the current MSP extension proposal should be modified to address these concerns. First, patients with CKD realize that their treatment is costly, and they worry that employers will discriminate against individuals with kidney disease or those who are at risk of developing CKD (e.g., patients with high blood pressure or diabetes—the two leading causes of kidney failure). We believe that there need to be provisions in the MSP extension to protect patients—we want to make sure patients do not lose their jobs based on health-associated discrimination.

### Renal Support Network

Second, patients are concerned that insurance companies will take steps to reduce costs, and that the "cost efficient provision of healthcare" may not be in the best interest of the patients who depend on dialysis for their lives. Examples of potential cost cutting measures that our members have voiced include limiting the number of dialysis treatments in a month, or only contracting with a limited number of dialysis facilities (which may not be located close to patients—this could be disastrous, especially for those in rural areas). We recognize that there are laws that protect us from this type of discrimination, but we want to ensure that any change in the MSP is accompanied by a strong statement that continues to protect patient rights.

Third, some individuals who are entitled to Medicare solely on the basis of having ESRD may have problems if they drop their health insurance during the MSP period. If they live in one of the 22 states that do not sell Medigap plans to ALL Medicare beneficiaries, they will have no secondary insurance coverage if they drop their private health insurance and switch to Medicare. While Michigan is NOT one of those states, this loophole in healthcare coverage needs to be addressed in federal legislation, and has been in Rep. English's bill, HR1282. I call this bill to your attention and hope you will help us address this problem in the near future.

We acknowledge the potential objections that have been raised against the MSP extension, but believe that a careful review will show that these arguments should not be roadblocks to the passage of this provision. For example, some object to the MSP because they fear that the longer an individual is covered primarily by their private health plan, the greater the chance that they could begin to approach their plan's lifetime cap and/or their comprehensive family lifetime cap. This would, of course, depend on the individual's overall health care expenses and their family situation. While this is a potential concern, we believe that affected patients could choose to switch to Medicare at any time DURING the MSP period. Nothing in the CHAMP provision would prevent them from making that decision, so RSN believes it is in an individual's best interest to have the *choice* to stay covered primarily by their health plan for the proposed 42 months.

We also believe that it was ludicrous for AAKP to object to the MSP extension based on the argument that "ESRD patients have a life expectancy of 60 months," and that as a result "…delaying Medicare for 42 months would mean most patients would never even live to see the benefits of Medicare as primary payer."

We don't deny that our life expectancy is less than that of individuals without kidney failure. However, I need to point out that the mortality statistics for patients with ESRD are very misleading because many patients are elderly. Table H.31 on page 236 of the US Renal Data System 2007 Annual Data Report (<a href="www.usrds.org">www.usrds.org</a>) displays the expected life expectancies for beneficiaries on dialysis. The data is clear that only patients over 60 years of age have a life expectancy that is below 5 years. Many ESRD patients under that age have life expectancies well over 5 years. Many patients have been on dialysis or a combination of dialysis and kidney transplantation for many decades. In my case, I have had kidney failure since the age of 12, and am now 41 years old!

# Renal Support Network

RSN appreciates your consistent support of patients with kidney disease and the entire kidney care community, as reflected by your cosponsoring the Kidney Care Quality and Education act of 2007 (KCQEA). It is our hope that the savings Medicare receives from the implementation of the MSP will help pay for provisions that are in the KCQEA bill that include:

- **Ø** Home dialysis: Seeking to understand the barriers to the adoption of different treatment modalities by patients.
- **Ø** Education: Providing educational sessions for Medicare beneficiaries with Stage IV CKD to teach them how to slow the progression of the disease.
- **Ø** Awareness: Creating public and patient education initiatives to increase awareness about CKD and to help patients learn self-management skills that prevent and control CKD.
- **Ø** Reimbursement: Establishing a three-year Continuous Quality Improvement Initiative that would reward providers for quality improvement and outcomes. If the provider meets these goals, they receive a bonus.
- **Ø** Technicians: Establishing a uniform training for patient-care dialysis technicians.

These provisions are necessary to ensure quality care and education in the kidney community. To date, 160 members of Congress have supported this important legislation.

We believe that extending the MSP to 42 months is another provision that is in the best interest of patients and the entire renal community, and urge you to vote for the extension. We look forward to your continued support, and an ongoing dialogue on how to provide the best care for the hundreds of thousands of patients with kidney disease in the United States.

Thank you for considering our request, and please have your staff contact me at 818-284-6763 if I can provide any additional assistance on this issue or other matters affecting the care of patients with CKD.

Sincerely,

Lori Hartwell

RSN President & Founder