



RSN Federal Sample Letter

Date

To: The Honorable Name of Legislator
Room and Building address
US Senate
Washington, DC 20510

Reference: Renal Support Network Patient Priorities:
Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Recipients
Act of 2009 (H.R. 1458 and S. 565)
Supplemental Medicare Coverage Availability -Universal Medigap Access for
Beneficiaries (S. 1669)
Proposed Prospective Payment System Implementation and Quality Metrics
Congressional Kidney Caucus

Dear **Representative or Senator Last name:**

I am a patient activist for Renal Support Network's (RSN) weKAN, a national patient-run advocacy group whose purpose is to improve the lives of fellow patients living with kidney disease. As your constituent, I would like to request the opportunity to meet with you during the August Congressional recess in your home district office to provide you with my firsthand experience and knowledge regarding how certain legislation will help improve the quality of care for people with kidney disease.

(Modify the following - tell your story.)

I have had end-stage renal disease since 1968 and spent 12 years on dialysis until I was fortunate enough to receive a kidney transplant. Individuals with kidney failure face a life-time of dialysis, if they are not fortunate enough to receive a kidney transplant. Because of the shortage of organs, most of the more than 500,000 Americans with kidney failure must receive dialysis treatments a minimum of three times a week. The two primary causes of kidney failure are hypertension and diabetes.

RSN Has Identified and Prioritized Several Issues That Can Help Improve Patient Quality of Care While Potentially Lowering Overall Costs

Issue 1: Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Recipients

The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Recipients Act (H.R. 1458 and S. 565) will benefit organ transplant recipients who must take immunosuppressive drugs for the life of the transplant to prevent the body from rejecting the organ. Although the increased

access to care that is part of this year's health care reform law may help in this, there are no guarantees that transplant recipients will be able to have these medications covered. Currently, Medicare pays for most kidney transplants but covers drugs for only 36 months after the transplant as part of the Medicare end-stage renal disease (ESRD) benefit. After that, kidney recipients must pay for immunosuppressive drugs through private insurance, public or pharmaceutical programs, or out-of-pocket. Many patients are not able to afford the additional expenses and/or co-pays, and consequently may not be able to continue to take these organ-preserving drugs. (Medicare does cover drugs without a time limit if the patient qualifies because of age or disability status.)

Immunosuppressive drugs are expensive, but the alternative is even more costly. Medicare spends \$17,300 per patient on anti-rejection medications to maintain a transplant, but if the kidney transplant fails, the person returns to dialysis at a cost of over \$68,600 per year to Medicare. And because dialysis is physically draining, quality of life often suffers too.

Request: Support the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Recipients Act and prevent people from needlessly losing their transplanted organs and returning to dialysis simply because they cannot afford their medications. Please support the continued good quality of life for kidney transplant recipients by signing on as a cosponsor of this bill if you have not already done so.

In addition to the preservation of transplanted organs, we are also very interested in nationwide efforts to encourage organ donation. With more than 100,000 people on the organ transplant waiting list, and 83,000 of those waiting for a kidney, an initiative to improve donation rates is critical to address current organ shortages. We urge you to support the reintroduction of bills for pilot projects that examine the effect of incentivizing donation or altering the designation process so that more individuals realize the importance of becoming an organ donor.

Issue 2: Medicare Supplemental Policies to be Made Available for People Under the Age of 65

We also ask for your support of a federal requirement to make Medicare Supplemental policies or Medigap policies available to all Medicare recipients—including those in the ESRD program.

Currently, this protection does not extend to people who enter the Medicare program prior to the age of 65 due to disability or ESRD. Due to this oversight, many people with disabilities who are under the age of 65 with ESRD on dialysis are unable to access critical medical services (e.g., kidney transplants and prescribed medications) unless they have access to private insurance or the state's risk pool program (where they are subjected to cost prohibitive premiums). As a result, many of these individuals must turn to the Medicaid/Medigap programs for financial support.

Fortunately, **31 states have already taken action to close the "Medigap Gap"** by extending access to Medigap coverage to people under the age of 65 who enter Medicare due to disability or ESRD.

States that offer full or limited coverage include Colorado, California*, Connecticut, Delaware*, Florida, Georgia, Hawaii, Illinois, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts*, Michigan, Minnesota, Missouri, Mississippi, New Hampshire, New Jersey, New York, North Carolina, Oklahoma, Oregon, Pennsylvania, South Dakota, Tennessee, Texas, Vermont* Washington and Wisconsin.

*Limited coverage

Unfortunately, **19 states have not yet extended access to Medigap coverage.** This puts citizens' health at risk and imposes significant cost on the Medicaid program and taxpayers.

Request: Expand Medigap access to those who enter the Medicare program prior to the age of 65 due to disability or ESRD, including those with kidney transplants. Although not among the provisions of the health care reform bill, this access is urgently needed, and we would encourage you to please support the tenets of S. 1669, the Equal Access to Medicare Options Act of 2009 introduced by Senator John Kerry, to provide all Medicare beneficiaries with the right to guaranteed issue of a Medicare supplemental policy. A companion bill needs to be introduced in the House Overall, we believe that this change in coverage will lead to Medicaid savings and protect taxpayers from escalating costs

Issue 3: Proposed Prospective Payment System Implementation and Quality Metrics

Public Law 110-275, the Medicare Improvements for Patients and Providers Act, will affect the provision of care for patients on dialysis.

The revised payment system will be implemented in 2011, and the proposed rule, which is still being finalized at this time, includes limited quality metrics for anemia and dialysis adequacy. It is our understanding that additional quality metrics that are being considered for the future include vascular access, fluid management, infection control, and bone and mineral metabolism. However, these laboratory-based parameters only provide part of the story regarding patient quality of care and outcomes. We would urge the addition of a process measure the gauge the patient's experience during dialysis treatments, and a measure reflecting the rehabilitation status of patients and their ability to work. Both of these factors provide a true measure of the effectiveness and outcomes of the care that is provided.

Request: The bundled payment system will be the biggest change since the ESRD program was enacted in 1972. As patients, we are worried about quality of care and hope to receive optimal care instead of adequate care.

Issue 4: Congressional Kidney Caucus

We encourage you to join us in our efforts to maintain the Congressional commitment to individuals with kidney failure by acting now. In addition to the issues outlined above, your support of the ESRD community and its patients could be demonstrated by joining your colleagues as a member of the Congressional Kidney Caucus. Nearly 30 million Americans are currently progressing through the stages of chronic kidney disease (CKD), and over 505,000 have irreversible kidney failure and rely on dialysis or a kidney transplant to survive. The two main causes of kidney failure are high blood pressure and diabetes, which are affecting many more individuals at younger ages. A nationwide campaign—spearheaded by a knowledgeable and supportive Congress—is required to address this growing epidemic and provide proactive, high-quality, and cost-effective care to those who are affected.

Request: Join the Congressional Kidney Caucus. For more information, contact the staff of the Caucus co-chairs—Congressmen Jim McDermott (anne.grady@mail.house.gov) or Mark Kirk (shauna.mccarthy@mail.house.gov).

We appreciate the sweeping changes in legislation and regulatory policy that have taken place over the last few years, and are optimistic that these changes will improve both patient quality of care and cost effectiveness. I welcome the opportunity to meet with you to discuss our suggestions for ensuring that both of these goals are met simultaneously. I will call your office within the next week to see if I can arrange a meeting with you and/or your health legislative aide to discuss these important issues while you are on recess in your home district.

Thank you so much for your interest and support.

Sincerely,

Your name
Address.
Phone
Email info