Lori Hartwell
Founder/President

Malia Langen
Chairman of the Board

Susan Vogel, RN
Treasurer

Linda Oakford
Secretary

Board Members:
Rhonda Brooks
Sara Carlson, RD, CDE
Jeffrey Davis
Marlene DeCenzo
Stephen Furst
Jacki Harris, RN
Lori Hartwell
Maria Hsieh, RN
Kerri Jacobson
Michael Josbena, RPh
Lana Kacherova, RN
Malia Langen
Linda Oakford
Susan Vogel, RN

March 5, 2009

Dear President-Barack Obama and Health Secretary Kathleen Sebelius:

Re: The Ten Point Plan: Renal Patient's View on Healthcare Reform for People with Chronic Kidney Disease

The Renal Support Network (RSN) is a patient-run, patient-centered advocacy and education organization that strives to help patients with chronic kidney disease (CKD) improve their employability and develop their personal coping skills and special talents. RSN's education and empowerment programs enable patients and family members to take control of the course and management of this chronic disease.

CKD affects over 25 million people in the United States and has been recognized as an emerging epidemic that disproportionately affects those at highest risk (i.e., the economically-deprived and minorities). Over 400,000 of us require either regular dialysis or a kidney transplant to live and the quality of care that we receive directly affects our life expectancy, quality of life, and contributions to society.

We who have CKD are appreciative of the assurance of care provided by the Medicare ESRD program, which allows us access to the life-saving therapies of dialysis and transplant. We also have experienced firsthand how administrative decisions regarding quality of care and payment structures have significantly impacted our quality of care and our ability to live. We would like to offer the patient's perspective on the ongoing challenges and concerns about the care that is offered to individuals with CKD, and how this care can be delivered in smart and cost effective ways.

We have a significantly vested interest in the outcome of your examination of the healthcare system in the United States and appreciate the opportunity to provide input and feedback on potential health care reforms.

Renal Support Network • A 501(c)(3) non-profit organization • EIN #95-4672679 • info@RSNhope.org
1311 N. Maryland Ave., Glendale, CA 91207 • Phone 866-903-1728 • Fax 818-244-9540 • www.RSNhope.org

1. Involve Patient Survivors/Advocates in Solving Health Care Problems in CKD

RSN would recommend the creation of one national patient-centered committee dedicated to helping meet the needs of patients with CKD and provide feedback to CMS. Long term survivors have a unique perspective as a result of living with kidney disease and all of its ramifications and need to have an active voice in how to improve the healthcare system. This Kidney Patient Quality Committee (KPQC) could develop educational materials and best practices for patient adherence as well as resolve complaints and grievances. KPQC could also employ available resources to examine issues and to develop measures that are of importance to the patient. The results would be maximum patient involvement, better dialysis adherence and significantly improved outcomes. This new structure would be independent and report directly to CMS. Oversight should be mandatory for any program involving financial resources and human lives. KPQC would request that the oversight entity include an understanding of the renal community at-large. Involving all national patient organizations will help market the patient-centered structure and allow us to create standard uniform educational/resource material for distribution to CKD patients and to reduce duplicative resources.

The KPQC would be responsible for the following actions:

- Provide recommended Quality-of-Life standards of ESRD for dialysis providers and insurance carriers.
- Provide an annual report on the number of ESRD patients employed that includes opportunities, barriers, and identified needs.
- Recommend state and federal legislation that would assist as many ESRD patients as possible in returning to the workforce.
- Provide a voice for kidney patients that are independent of financial ties to the industry.
- Provide recommendations to CMS on the ESRD Medicare program.
- Understand and communicate the barriers to quality care and develop strategies to overcome these barriers.
- Provide a central location/website for patients to contact for educational information (links to all patient organizations), for help with a problem facility, or to submit ideas to improve their facility.
- Develop “best practices” for patient involvement to optimize government spending on ESRD.
- Analyze the potential benefits and risks to ESRD patient care.
- Identify needed new product development.

This organization would pay for itself by recommending changes that would

1. Result in more patients returning to the workforce.
2. Reduce wasteful spending from duplication of efforts.
3. Educate fellow patients so they will be healthier thus reducing hospitalizations.

2. **Provide coverage for immunosuppressive medications, necessary to maintain the viability of a kidney transplant, to protect the life and health of the recipient and to invest in the organ donation process.**

   This proposal is a combination of common sense, good medicine, and good practical economics. Once an organ is transplanted, certain anti-rejection medications are required to maintain the transplant. Currently, patients who receive a kidney transplant only receive reimbursement for these medications for 36 months following the surgery—despite the fact they must take these medications for the rest of their lives. If the individual is unable to obtain other insurance coverage after 36 months and cannot afford the cost of these very expensive medications, they often are forced to discontinue the immunosuppressive, lose their transplant, and end up back on dialysis unnecessarily. Not only can this be devastating to the quality of their life and health, but in economic terms, it costs far less to maintain a transplant than to support the cost of dialysis annually. In short, the government will save money and saves lives by using our approach.

3. **Ensure that the quality indicators used by the government's ESRD Clinical Performance Measures (CPM) project actually reflect good quality care.**

   The CPMs were reissued in April 2008 with the purpose of providing an ongoing measure of the quality of care that is being provided to patients on dialysis. These performance measures are: dialysis adequacy, anemia management, mineral metabolism, vascular access and the Kidney Disease Quality of Life (KDQOL) assessment. Benchmarks are created for dialysis adequacy, anemia management, mineral metabolism, and vascular access, but facilities are not required to report the score of the KDQOL. For example, the new CPMs require facilities to conduct a Kidney Disease Quality of Life (KDQOL) assessment, but the rule does not establish target scores or require facilities to report their mean and median scores. Also, providers are required to report the patient's work status upon initiation of dialysis, but this measure is not followed up upon. Half of the patients on dialysis are still of working age and employment needs to be reported. This is another example of one of the measures that is important for patient's quality of life.

   Emphasizing the quality of life and health as measures in the delivery of health care, including preventive care, gets at the very purpose of health care. This has begun under the new CMS ESRD Conditions of Coverage wherein measures of quality of life and health are being implemented as metrics for defining good quality treatment and care received from providers. In both the treatment and preventive care, this needs to become the rule rather than the exception. After all, if improving an individual's health is the very point of health care, then we need to move from meeting "adequate dialysis" measures to "optimum dialysis" ones, so that our health care dollars are most effectively used.

   Most importantly, the revised quality standards should be established before the currently proposed bundled payment system is implemented and a standard a mean quality of life number needs to be established and defined.

   In addition, we recommend reevaluating the process of dialysis facility inspections. Currently facilities are inspected once every three years. However, we believe more frequent inspections are warranted especially when quality standards are changing. Also, timely inspections of new facilities are necessary to accelerate the expansion of home based dialysis programs, all of which require government certification.

4. **Make Medigap coverage access universally available**

Currently, for ESRD patients under the age of 65, there is no universal provision for access to Medigap or supplemental insurance to encompass those items and services not fully covered by Medicare. Only 26 of the 50 states offer some kind of Medigap coverage. Since the ESRD program provides Medicare to everyone affected by and receiving treatment for renal failure, this leaves those renal patients under the age of 65 choosing either to pay potentially huge out of pocket costs or to compromise their treatment by picking and choosing what they can afford. A national requirement that these patients have access to Medigap coverage in every state, with rolling admission, would guarantee that the full range of services required maintaining their health is available to them.

5. **Provide support and incentives for self care, home treatment and more optimal modalities**

Dialysis treatments are a good paradigm for what "home" care can mean, by maintaining the best quality of life for a patient and by helping them stay actively employed. Currently, though, there are no reimbursement provisions for awareness and training programs to encourage patients to choose home treatments. Economically, home modalities have the added benefit of freeing up medical staff time and resources. Creating incentives for home dialysis will not only address the ever increasing health care staff shortage, but will also help alleviate the transportation obstacles. This would further be accomplished by providing incentives for those modalities considered optimal as opposed to adequate: these include more frequent treatments such as short daily dialysis as well as longer and slower treatments such as nocturnal therapies. These are also most typically, although not exclusively, done at home. Studies of patients with access to these treatments have shown them to be generally healthier, needing fewer medications and requiring much less frequent hospitalization. All promote a better quality of life for the dialysis patient, again making them more likely to be employable.

6. **Develop community awareness and prevention education to address the CKD epidemic**

Since hypertension and diabetes are the leading causes of kidney failure, it would behoove the government to take an active role in public awareness and prevention of these conditions. Many people are aware of the link between hypertension, stroke, diabetes and cardiovascular problems, but the vast majority of the general public are surprised to learn the connection to kidney failure. For the aging population and the burgeoning of the baby boomer generation who are most vulnerable to these conditions, money spent on prevention and screening programs for these precursors would be well spent. Monies spent now would save money in the long run.

Additionally, early awareness of a problem allows patients to become engaged in their own care in order to slow and even prevent the progression of these disease processes. The result is an overall healthier population and fewer dollars needed for health care. Part of the MIPPA legislation requires 3 CKD pilot projects in three states to be conducted starting in 2009, which is a great start.

Recognizing that there is a shortage of physicians, nurses and other health professionals to provide this education, we would like to suggest that patient "peer" educators, especially long time survivors, would be a valuable resource in this process. Not only would the patients have instant credibility with fellow patients, and have valuable information to offer by virtue of their experience, but such a program would also return to the work force a valuable segment of the

population. They would be contributing members of society in roles that they are uniquely qualified to perform. These chronically ill people would have an opportunity to return to work or stay employed.

7. **Explore options for increasing organ donation rates**

   Current waiting list numbers for organs in the United States exceed 100,000. Of this group, 75,000 wait for a kidney. And with 18 people dying every day while lingering on the waiting list, a strong effort to increase the rates of organ donation needs to be undertaken.

   There were several bills before the last Congress to address this problem. The rationale behind each of these plans needs to be studied so a source of action can be implemented quickly to address this shortage, and a new bill introduced and passed. Whether it is to be a philosophical shift to a presumed consent and "opt-out" program, as several European countries have, or greater access to paired donation possibilities, or an examination of a financial incentive program, it is critical that this be done as soon as possible. We must stem the tide of those dying on waiting lists when far too many organs that could be made available are wasted. Also, living donors need to be protected by ensuring them access to ongoing healthcare. It also must be illegal for insurance companies to deny donors coverage simply because they donated a kidney.

8. **Take down the wall between Medicare A & B**

   Medicare currently separates payment for inpatient and outpatient care, so investments in measures that would keep patients healthier and out of the hospital are difficult to make since they are not reimbursed by Part B of Medicare. The savings resulting from fewer hospital days are accrued to Part A of Medicare and thus are not available to offset the costs of Medicare Part B. This is unfortunate since not only could patient outcomes be improved, but total costs of care could be reduced. In the case of dialysis patients, they require immediate attention to vascular access complications and are often admitted to the hospital. It would be helpful if these services could be provided and coordinated by the dialysis center. This would reduce the number of hospitalizations for a typical kidney patient. Currently there is no interest in doing so because the funding for Medicare A and B comes from different "pockets." Taking down the wall between Medicare A and B has the added benefit of maintaining kidney patients in a healthier state with a better quality of life which, after all, is the very point of any good health care program. If all incentives are aligned, it would prevent cost shifting.

9. **Address access to care as a multi-dimensional challenge**

   In considering access to care, it is important to note that there are still disparities across racial lines, in rural areas and for those served by small providers; access to quality care is not an equal thing in this country. By paying particular attention to the special needs of these populations, we can make the delivery of health care more equitable and increase the quality of many patients' lives. One example is transportation for dialysis. While the treatments themselves are provided, getting to the center for the treatment can be a complicated procedure with various transport companies involved. It often means a lengthy journey of up to 3 hours each way, certainly a hardship on any patient. These practical considerations are often missed in the health care access discussions, and could be addressed by creating incentives for increasing home care or paying for and increasing non-

emergency transportation options. In the case of dialysis, every treatment is an emergency. If the patient does not attend their regular scheduled dialysis treatment, they will end up in emergency which is more costly.

10. Consider promoting the "medical home" concept of healthcare reform that is supported by the American Medical Association (AMA) and other leaders

The medical home model is defined by the Association of American Medical Colleges (AAMC), which has given a preliminary endorsement to the approach, as a concept or model of care delivery that includes an ongoing relationship between a provider and patient, around-the-clock access to medical consultation, respect for a patient's cultural and religious beliefs, and a comprehensive approach to care and coordination of care through providers and community services.

According to experts in the medical community, we are currently so focused on acute care that people only seek help when they have a new problem or have exacerbated an existing problem. We lose a lot of opportunities for preventive care, coordination, and patient education this way. The medical home model is about agreeing that there are core functions that need to be fulfilled. If you're a patient who has cancer, you may have 10 doctors taking care of you if you have chronic conditions on top of the cancer. From the patient's perspective, the system is un-navigate able and they need an advocate and a central resource.

The medical home, or at least its theoretical version, seems to enjoy almost universal support—patients would benefit from a simpler, more personalized health care experience, while doctors and their care teams would have more support for their "legwork" and more time to focus on their principle interest—the patient.

Again, in light of the monumental task involved in reforming our health care system in the best interests of patients and to ensure the quality of life and health of this nation's citizens, we urge the formation of an advisory network of consumers; patients, family members and care partners. No one knows better the difficulties of navigating the landscape of the current health care system. Recipients of health care can best point the way to a model of care that is efficient and effective, fair and equitable in its delivery of services. The main reason for providing health care at all is to improve the quality of the lives of all individuals. We ask that you include educated and genuinely proactive patients and family members in any major decisions to healthcare reform.

We thank you for considering the tenets of our health care reform proposal with regard to patients with CKD, and look forward to an ongoing dialogue on these issues. The patient advocates from the Renal Support Network would be happy to provide proactive and ongoing feedback as your administration evaluates and reforms the healthcare components that are vital to those with CKD.

Sincerely,

Lori Hartwell
RSN Founder/President