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Chairman Johnson, Ranking Member Becerra, and members of the subcommittee. Home Dialyzors United, formerly NxStageUsers, is a 501(c)(3) non-profit and the largest dialysis patient organization in the nation dedicated specifically to home dialysis, representing over 500 patients or approximately 10% of home hemodialysis patients in the U.S. On behalf of those members, and others doing in-center dialysis who can't speak for themselves, we are writing to comment on **Securing the Future of the Social Security Disability Insurance Program.**

As we all know, the United States is facing an extreme deficit dilemma. As a dialysis patient organization, our first call is to do no harm. However, we also recognize the drain CKF patients have on Medicare expenditures and Social Security Disability Insurance benefits. Presently, people with chronic kidney failure (commonly known as ESRD) consume 8% of the total Medicare budget while numbering approximately just 1.8% of the population (570 thousand/309 million).

There are no hard numbers regarding SSDI, but we do know over 96,000 dialysis patients between the ages of 18-54 were unemployed in December, 2009¹. At an average cost of \$1070 per month in SSDI benefits, the total cost of SSDI for this population alone is estimated to be nearly \$ 1.24 billion per year. We obviously don't expect all of the unemployed will be able to work, but do know many would if they could and if they felt well enough and believed their Medicare coverage would not be put in jeopardy because of their employment.

We also recognize that those unemployed are not able to contribute fully to their family's fair share of income taxes. With an average U.S. per person tax of \$3,804, this alone represents a total loss of revenue of nearly \$365 million per year from this dialysis population alone. Once again, we recognize these figures are very rough.

For these reasons alone, we believe a study of the economic impact of renal rehabilitation should be undertaken by the GAO with its resultant report provided to the Ways and Means Committee's Social Security and Health Subcommittees.

1) End Stage Renal Disease Network Organization Program, Centers for Medicare and Medicaid Services, 2009 Summary Annual Report, Table 20.

The original intent of the Medicare provisions for End Stage Renal Disease, forthwith called Chronic Kidney Failure or CKF, was to primarily rehabilitate patients so they can be employed and productive. We understand the complexion of the CKF population has drastically changed since the laws were written in 1972 and much of the patient community has aged. But a significant number are not of retirement age. It is these patients to whom we refer here.

During the last four decades of the government CKF entitlements, we have seen a drastic reduction in the utilization of home dialysis modalities, from nearly 40% of patients, to less than 10% of the current dialysis population. Home hemodialysis, which represents less than 2% and peritoneal about 7% of the total on dialysis is a mere fraction of what it should and could be. Contributing to this issue, less than half of the dialysis clinics in the US are certified to offer Home Peritoneal Dialysis, and only 15% of these clinics offer Home Hemodialysis. This, even though home hemodialysis has been shown to dramatically improve survival on dialysis; and, home dialysis patients are more than twice as likely to be employed as their counterparts treated with in-center dialysis.

The in-center dialysis clinic is the place where approximately 353,000² patients receive their therapy, but only 24% of U.S. dialysis centers have patient shifts available after 5:00pm. There is a direct correlation between these figures for shifts after 5:00pm and the number of patients unemployed.

We strongly recommend that Congress direct CMS to develop guidelines for increasing the number of patients offered home dialysis, as well as to increase the number of facilities offering patients the option of dialyzing after 5PM. By rectifying this situation we believe a significant impact could be attained in reducing the U.S. deficit problem. In addition, we can return the dialysis environment from one of forced debilitation in dialysis centers to a progressive approach of affording people a healthier and more purposeful life.

We obviously do not want benefits taken away from dialysis patients. Almost none of the patients would survive without the Medicare entitlement. Unemployed patients and their families would also suffer extreme financial hardship without Social Security Disability Benefits. However, with optimal dialysis therapy, many not of retirement age would be able to be employed and not exacerbate the drain of government expenditures.

Unemployment in the dialysis population is not simply driven by physical and economic issues, but is multi factorial in scope.

Many people when first starting dialysis have jobs and are physically able to continue employment. However, many subsequently quit their jobs because few in-center units offer after 5:00pm shifts. Other patients are not even made aware of home modality alternatives. Imagine a person who is

2) End Stage Renal Disease Network Organization Program, Centers for Medicare and Medicaid Services, 2009 Summary Annual Report, Table 12.

assigned a Monday, Wednesday, Friday shift that starts at 6:00am and ends at 10:30am. That 10:30 ending time does not take into account either the lengthy post treatment procedures or the physical recovery time. Transportation to and from a sometimes inconveniently located center must also be factored into the total length of treatment. In another scenario, a patient may be assigned the second shift which might run from 11:00am to 3:30pm. As one quickly realizes, a dialysis patient who has a job would find it nearly impossible to continue.

As a totally patient focused organization that strongly believes in renal rehabilitation, Home Dialyzors United stands ready to provide any further information you may need. We feel it is imperative that the committee thoroughly understand the patient and care partner perspective.

Home Dialyzors United urges the Way & Means Social Security Subcommittee to examine the impact of the current dialysis operating environment on the ability of Medicare beneficiaries to continue employment and to avoid becoming dependent on Social Security Disability Insurance.

Thank you for the opportunity to comment to the committee.

Respectfully,



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