

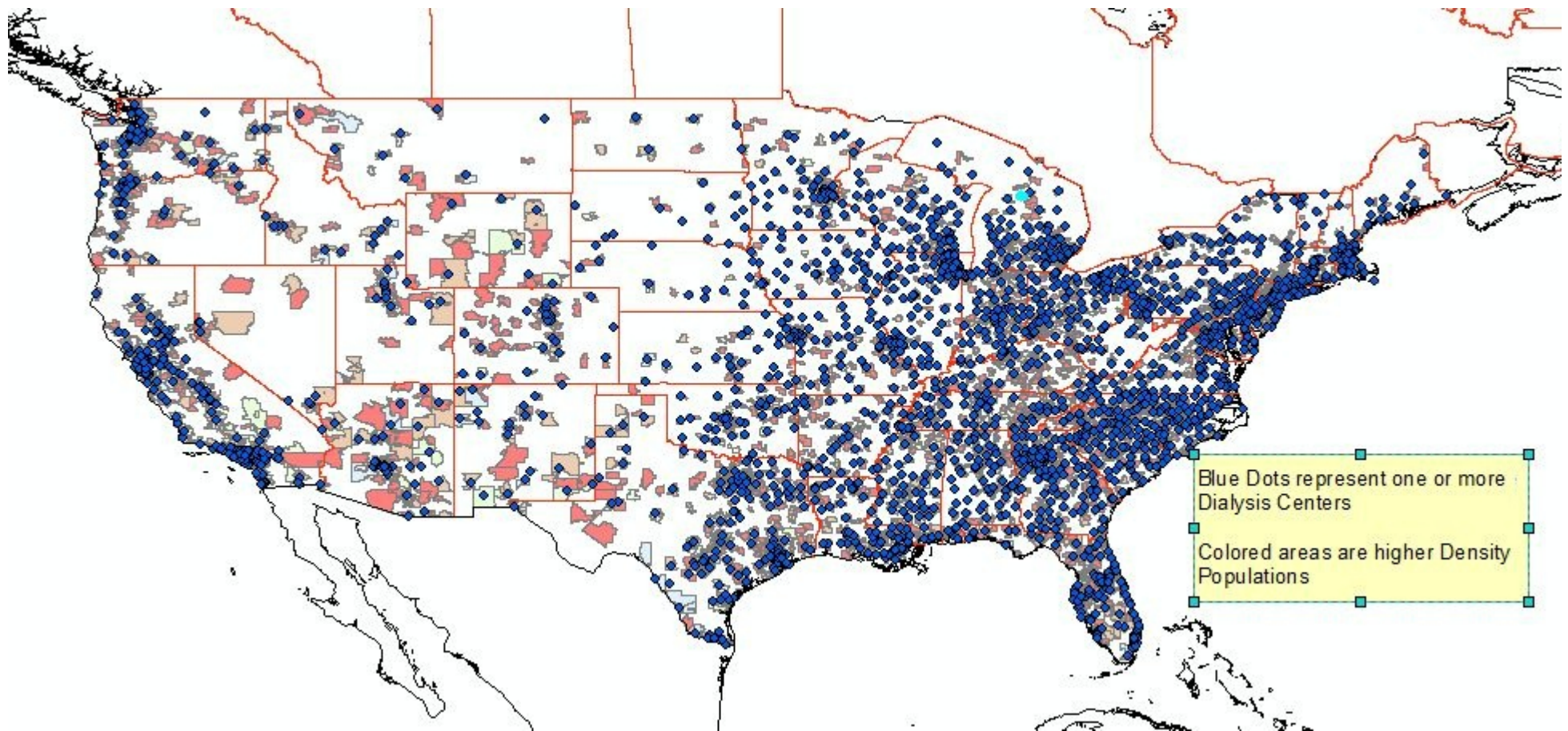
# The Dialysis Report: Transportation Demand Outstrips Supply

By Scott Bogren

Everyday, thousands of Americans who need regular kidney dialysis board a community or public transit vehicle to access this life-sustaining care. The trips these patients take are time-consuming — they often last

more than four hours in duration — and essential, as they absolutely must be made, regardless of the weather or any other circumstances. Dialysis trips also are changing the nature of public transit in many communities.

The role of providing transportation for dialysis treatment has long been an area of challenge — as well as accomplishment — for community, public and human services transportation. Early outpatient dialysis treatment created significant needs for



demand-responsive transportation services in communities of all sizes. Since, initially, many of the clinics providing dialysis were located in urban areas, transportation in rural communities took on greater importance for patients and their families. In the ensuing years, the growth in the overall number of dialysis patients brought increased needs for responsive mobility services in urban and suburban areas, too.

The regular and consistent need for dialysis treatment requires similar consistency in transportation access. Paratransit services, rural public transit, human service networks and volunteer programs not only provided many of these life-sustaining trips, but also raised funds to support them. Although public funding helped with purchasing equipment or even operating costs, many programs needed to raise local funds to meet various match requirements or to meet the needs of individuals that didn't fit into some categorical program or individual eligibility requirement. In one of the greatest and often undisclosed success stories, these transportation providers and networks made dialysis treatment possible for millions of Americans — and changed many people's lives.

Over the last 30 years, dialysis transportation services have made it possible for patients to stay in their homes and in their communities, thus greatly lowering the overall cost of providing the treatment. And although these efforts stretched the resources and ingenuity of the nation's transportation services — the

need for dialysis transportation was met day-in and day-out across the nation.

The significant growth of dialysis treatment — as is detailed later in this report — makes daunting the prospect of continuing to meet the demand under the current structure. It seems that one of our nation's greatest medical challenges is equally a test of our transportation system. Across the nation those who created the current dialysis mobility solutions are faced with dramatic increases in demand as the number of dialysis patients and the number of clinics — which often work on a 24-hour basis to serve more patients — require both additional resources and tools. Because there are many patients needing evening services and since many patients experience difficulties with treatment, there are now needs for more individualized dialysis transportation service strategies that are more expensive to provide.

For community and public transit operators, these trips are a mounting challenge. Demand for dialysis transportation, according to every transit manager interviewed for this article, is skyrocketing at the same time payment mechanisms dwindle. Trips distances have grown even as available dialysis center chairs are expanded locally to keep up with the number of patients. What is needed today, clearly, are new solutions, new partnerships and new thinking.

"We've reached the tipping point," says Santo Grande Executive Director of Del-

marva Community Transit, headquartered in Maryland's rural Eastern Shore. "We just don't have the resources to meet the need — vehicles, drivers and money."

## The Dialysis Transportation Task

Dialysis is a process by which excess waste and water are removed from the blood of patients whose natural kidney filtration system is no longer effectively functioning. Typically, individuals on dialysis have moved from one of the first four stages of chronic kidney disease and into what is known as end-stage renal disease (ESRD). Physicians and researchers agree that once an individual is diagnosed with chronic kidney disease, they will eventually require either dialysis or a kidney transplant — the end stage for the disease.

Dialysis treatment frequencies and the duration of individual sessions are largely dependent upon the patient. That said, for more than 40 years the generally accepted standard of care for ESRD patients has been dialysis treatments thrice weekly, each at around four hours in duration. More recently, several studies have suggested that increased frequency in shorter duration treatments — six times a week for two-and-a-half hours — increased overall health and quality of life in patients. Needless to say, the mobility ramifications of this potential treatment schedule change are frightening as it would effectively double the current, necessary transportation service, a service that

many community and public transit systems already find daunting.

“We’re struggling to meet growing demand already,” says Jim Wood of Kennebec Valley Community Action in Waterville, Maine. “Doubling the service would be frightening.”

To undergo dialysis treatment, patients typically sit at reclining chairs with tubes leading from themselves into humming dialysis machines. Though life-sustaining, the process often wears out patients and leaves them susceptible to a number of side effects such as nausea, infection, bleeding and more. In fact, this bleeding — due to a patient’s inability to clot — was cited time and again in the preparation of this article as a chronic challenge with dialysis patients on community and public transit vehicles. In some cases, dialysis patients may be able to board a fixed-route community or public transit bus to get to their scheduled service. But the return trip, after the debilitating process, must be made on a demand-response service.

“In all honesty, the ability to use fixed-route transit for dialysis is limited,” says United We Ride Region 3 Ambassador Rex Knowlton, who managed dialysis transportation service in Philadelphia for more than two decades.

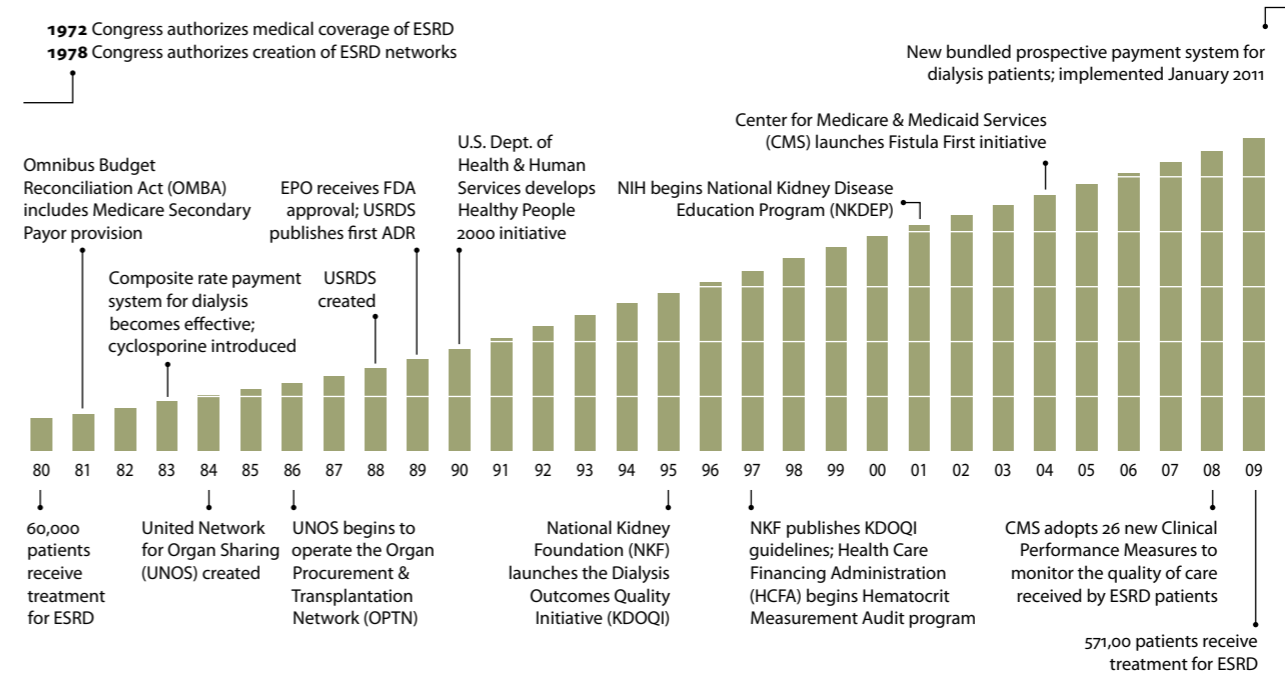
The regimentation of dialysis treatments creates additional health care and transportation costs, too. Typically, patients on a Monday-Wednesday-Friday schedule are more likely to be private-paid, particularly those receiving their dialysis in the middle of the day. Conversely, Tuesday-Thursday-Saturday patients and those early morning and later night clients are more likely to be Medicare patients. These are also the dialysis patients more likely to be dependent upon community and public transportation — in the most difficult and costly to serve time slots.

“The cost of off-peak and Saturday treatments is much more than an incremental cost increase to transit,” says Knowlton. “It’s a significant increase.”

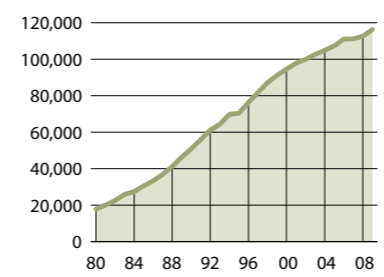
### ESRD By the Numbers

Today, the National Kidney Foundation reports that 26 million Americans suffer from Chronic Kidney Disease — a more than 20 percent increase since 1994 — with millions more at increased risk due to the increasing prevalence of such health risk factors as diabetes and high blood pressure. This figure represents approximately 13 percent of the adult population of the United States.

# end-stage renal disease (ESRD) IN THE UNITED STATES



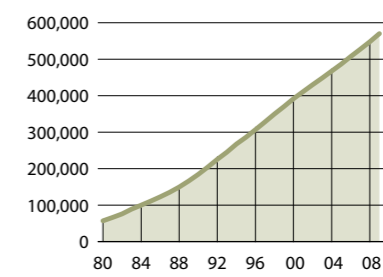
**New patients** More than 116,000 people began treatment for end-stage renal disease (ESRD) in 2009.



**1980** U.S. patients newly diagnosed with ESRD  
1 in 11,600

**2009** U.S. patients newly diagnosed with ESRD  
1 in 2,800

**Total patients** Nearly ten times more patients are now being treated for ESRD than in 1980.



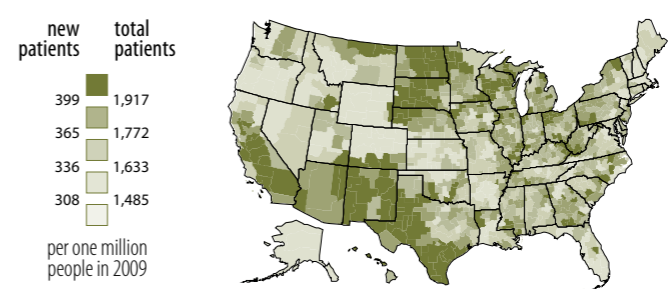
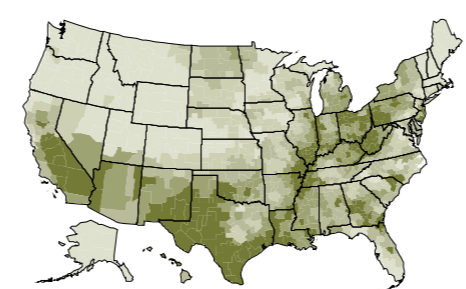
**1980** U.S. patients being treated for ESRD  
1 in 3,450

**2009** U.S. patients being treated for ESRD  
1 in 575

2011  
USRDS  
ANNUAL  
DATA  
REPORT

volume  
one  
esrd

page  
138



Graphs: Figure 1.1  
Rates of new & existing patients: Figures 1.6 & 1.12  
Maps: Figures 1.4 & 1.10

These accompanying charts, as well as many of the key statistics from this report, come from the The United States Renal Data System. USRDS is a national data system that collects, analyzes, and distributes information about end-stage renal disease in the United States. More specifically, we recommend the USRDS’s End Stage Renal Disease Atlas (link: <http://www.usrds.org/atlas.aspx>) as a key reference and resource.

Though smaller, the statistics are no less daunting for end-stage renal disease. More than half a million Americans are currently suffering from ESRD, the vast majority of whom require dialysis treatments to stay alive. Growth rates of ESRD are staggering. In 1980, 60,000 patients received treatment for the disease; 571,000 received the same treatment in 2009, a growth of 900 percent in 30 years. The rate of ESRD incidence is 355 per million population; the rate of prevalence of ESRD per million is 1,738. In 1980, 19,000 Americans began treatment for ESRD, as compared to 116,000 in 2009.

The rise in ESRD incidence has, not surprisingly, led to a significant rise in health care expenses associated with the disease and its treatment. Total Medicare ESRD expenses for 2009 came to \$42.5 billion — or \$82,285 per person per year for hemodialysis patients. Just over 1 percent of Medicare patients have end-stage renal disease, yet these same patients account for more than 8 percent of total Medicare spending.

The dialysis transportation challenge is so great that major changes in public policy must occur to enable this mobility link to continue. First the time has come to extend reimbursement for this vital health support service. Second there must be increased communication between those providing dialysis treatment and transportation.

## End-Stage Renal Disease Resources

- **End-stage kidney disease:**

- MedlinePlus Medical Encyclopedia**

- [www.nlm.nih.gov/medlineplus/ency/article/000500.htm](http://www.nlm.nih.gov/medlineplus/ency/article/000500.htm)

ESRD almost always comes after chronic kidney disease. The kidneys may slowly stop working over 10 - 20 years before end-stage disease results. ...

- **End Stage Renal Disease (ESRD)**

- American Kidney Fund**

- [www.kidneyfund.org](http://www.kidneyfund.org)

Learn about the causes, symptoms, and treatment of end stage renal disease (ESRD), also known as chronic renal failure (CRF) or stage 5 kidney disease. [Peritoneal Dialysis - Chronic Kidney Disease \(CKD\) - Hemodialysis](#)

- **End stage renal disease**

- Wikipedia, the free encyclopedia**

- [en.wikipedia.org/wiki/End\\_stage\\_renal\\_disease](http://en.wikipedia.org/wiki/End_stage_renal_disease)

End stage renal disease may refer to: End-stage renal disease, also known as chronic kidney disease (CKD), specifically the fifth stage of CKD; End Stage ...

- **End Stage Renal Disease (ESRD) Center**

- [www.cms.gov](http://www.cms.gov)

- [About CMS](#)

End-Stage Renal Disease Prospective Payment System (Publication Date: August 12, 2010); ESRDFacility Conditions for Coverage [PDF, 1.41MB]; FAQs ...

- **Welcome to the ESRD Network Forum Website Forum of ESRD ...**

- [www.esrdnetworks.org/](http://www.esrdnetworks.org/)

The Forum of ESRD (End-stage Renal Disease) Networks advocates for the organizations that monitor the quality of chronic kidney disease, dialysis and kidney ...

- **Medicare and People with End Stage Renal Disease**

- [www.cahealthadvocates.org/facts/1-002-CHAFactSheet.pdf](http://www.cahealthadvocates.org/facts/1-002-CHAFactSheet.pdf)

File Format: PDF/Adobe Acrobat - [Quick View](#)

Medicare solely on the basis of having ESRD even if you ... ESRD and who are not also eligible for Medicare ... Medicare eligibility due to ESRD, when coverage ...

- **The End Stage Renal Disease Network of Texas**

- [www.esrdnetwork.org/](http://www.esrdnetwork.org/)

The End Stage Renal Disease Network of Texas is to support quality dialysis and kidney transplant healthcare through patient services, education, quality ...

- **End Stage Renal Disease Network Coordinating Center - End Stage ...**

- [www.esrdncc.org/](http://www.esrdncc.org/)

The End Stage Renal Disease (ESRD) Network Coordinating Center (NCC) provides centralized coordination and support for the ESRD Network Program.

## Who Pays?

The crux of the transportation challenge is that the majority of dialysis patients are covered by Medicare, which — unlike Medicaid — does not offer non-emergency transportation as a benefit. Three out of four dialysis patients in the U.S., are Medicare primary, meaning that Medicare sets the reimbursement rate and pays 80 percent of that amount. Reimbursements include one rate for routine dialysis services and another for dialysis medications.

This leaves 20 percent of the typical dialysis charges to be paid by a secondary insurer. For roughly half of the Medicare primary dialysis patients, the secondary insurer is Medicaid, thus creating the so-called dual eligibles. How much of that 20 percent that Medicaid covers depends upon the state.

Recent studies indicate that only one in 10 dialysis patients are Medicaid primary, in which case Medicaid pays between 80 percent and 100 percent, depending on the state and its Medicaid plan. Finally, 10 percent of dialysis patients are covered through some form of private insurance.

Clearly, demographics and health care treatment trends are creating the steady growth of people needing dialysis transportation. At the same time, fewer dialysis patients have the ability to pay for the life-sustaining trips, which is taxing the ability of community and public transportation providers to

respond — particularly given the current constrained fiscal environment at federal, state and local levels.

“Twenty-five years ago when we first launched this service, it seemed to us that 90 percent of the dialysis patients we encountered were on Medicaid,” says Grande. “Today that equation has flipped, and 90 percent are on Medicare, which is why we’re hurting. I know it’s happened, but I don’t know why.”

Bill McDonald, executive director of Medical Motors in Rochester, N.Y., has seen the same transition: “We hardly do any Medicaid dialysis anymore, so our focus is on the patients who aren’t Medicaid eligible and who still very much need that ride.”

## The Transit Perspective

“The first thing you have to remember is that without the trip, these passengers won’t live,” says Ann August of the Santee Wateree RTA in South Carolina. “So when we receive a call requesting this type of service, we understand the ramifications and don’t want to say no.”

Indeed, in background discussions with community and public transit officials around the country for this article, a common refrain was the difficult position in which many transit operators find themselves — how to continuously add new dialysis patients to the transit schedule with no means of payment. Some worried that their general public service was, in effect, being usurped

by the swiftly growing dialysis transportation demand that is, in many ways, life-and-death.

“It’s terribly challenging,” says Jim Wood of KVCAP in Waterville, Maine. “We’re really concerned about our ability to continue meeting the growing demand without finding a way to pay for the service.”

At KVCAP, as with a surprising number of transit systems nationwide, the system reserves its local United Way funding specifically for this purpose. But community and public transit managers around the nation are reporting that these United Way funding sources, like many others, is not growing nearly as quickly as the dialysis transportation demand.

Another key issue some transit managers point to, is that the privately owned and operated dialysis centers — many of which operate from before 5:00am to midnight — seem to believe there is a statutory rule that prohibits them from actually paying a portion of the transportation costs to get their patients to their chairs. In researching for this article, we could find no such rule.

## A Different Kind of Solution

Of course, an obvious solution to the growing demand for dialysis transportation is to reduce the demand. A key component is the need for kidney donors across the U.S. In 2008, more than 16,000 kidney transplants were performed across the country with ei-

ther organs harvested from cadavers or from living donors. Today, the average wait time for a kidney donation can regularly exceed two years, at the minimum.

The Community Transportation Association of America is hereby calling on its members around the country to be sure to designate themselves organ donors and to work with transit employees and advocates to do the same. Transplants can add decades to people's lives and significantly forestall the need for dialysis, but only when the needed organs are available. For more on the National Kidney Foundation's organ donor programs, please click here: [http://www.kidney.org/news/end\\_the\\_wait/index.cfm](http://www.kidney.org/news/end_the_wait/index.cfm).

## Moving Forward

The key solution for community and public transportation, moving forward, is to develop a funding mechanism for dialysis transportation in Medicare. Currently, Medicare will only reimburse for emergency transportation services — read: ambulances — and not for non-emergency dialysis transportation. For Medicare, dialysis transportation is not an emergency.

“Yet we all know that not providing dialysis transportation results in life-threatening emergency situations that include both emergency transports and emergency room stays — both of which are exceedingly expensive to the program,” says Coordinated Transportation Solutions Executive Director

David White.

“If you're wondering what happens when we can't do the trip,” says McDonald, “the patients simply dial 9-1-1.”

Yet once a dialysis patient does dial 9-1-1, the Medicare program, in many cases, still refuses to pay. Just last month in West Virginia, for example, a private rural ambulance company paid a more than \$1 million penalty to Medicare for dialysis trips taken thrice weekly for two years by five local ESRD patients. The penalty was levied, not surprisingly, because Medicare inspectors had ruled that, “ambulances were not needed.”

Community and public transportation managers that were interviewed for this article were asked to roughly estimate the transportation costs incurred for a year of dialysis transports. Most came to a figure in the neighborhood of \$5,000 per patient, per year. When Medicare is paying more than \$82,000 per year per person for dialysis, it does not seem unreasonable to build in a 6 percent increase to ensure that the patient arrives safely and efficiently at the dialysis clinic to receive life-sustaining treatment.

“That's really the issue,” says August. “We are, by transporting dialysis patients, saving Medicare and the taxpayers a lot of money. We just can't keep up with the demand without a payment system.”

Additionally, new solutions, partnerships and thinking are necessary for both health

care and transportation providers to best manage the significant, continued growth in dialysis patients that researchers expect. A national dialogue between transportation providers and the dialysis industry, to include the National Kidney Foundation, must be a part of any short- or long-term solution.

CTAA Executive Director Dale J. Marsico, CCTM, considers dialysis transportation the foundation of all non-emergency medical transportation. “The dialysis transportation issue — because of the life-and-death nature of the service and the overwhelming demand — is the logical place to first focus when considering the role of community and public transit in health care provision and transportation,” says Marsico. “But it's really the first step of the long journey that CTAA and its members have embarked upon to bring together successful health care and transportation outcomes for the American people.”

## CT

*These accompanying charts, as well as many of the key statistics from this report, come from the The United States Renal Data System. USRDS is a national data system that collects, analyzes, and distributes information about end-stage renal disease in the United States. More specifically, we recommend the USRDS's End Stage Renal Disease Atlas (link: <http://www.usrds.org/atlas.aspx>) as a key reference and resource.*