IMPROVING PATIENT ACCESS TO HOME DIALYSIS

Numerous studies have shown that patients with End-Stage Renal Disease (ESRD) who dialyze at home, using either peritoneal dialysis (PD) or home hemodialysis (HHD) have a much better quality of life and excellent treatment outcomes, including increased survival rates and fewer hospitalizations. For most patients with ESRD, dialysis is the primary option when renal replacement therapy (RRT) is needed, and the overwhelming majority of these patients undergo dialysis in outpatient dialysis centers. Few of these centers offer home dialysis, and of those that do, most only offer PD. In fact, only 2 percent of dialyzors in the U.S. currently use HHD.

Home Dialyzors United (HDU) is working to improve access to home dialysis for all patients who wish to use this method of RRT, to promote unbiased education about all modality choices, and to ensure that efforts to promote the quality of dialysis treatment focus on improving the patient’s experience of care, treatment outcomes, and ability to lead a normal life.

Benefits of Home Dialysis

Home dialysis puts individuals with ESRD (and their families or care partners) in control of their treatment decisions. Home dialyzors are passively receiving medical services. Home dialyzors have flexibility in determining when and how to dialyze, more freedom to spend with family and friends, and more energy to pursue their interests, whether those include working, attending school, volunteering, or engaging in recreational activities and travel.

From a purely physiological standpoint, home dialysis is clearly superior. A functioning human kidney continuously filters the blood 24 hours a day, or 168 hours per week. However, the great majority of individuals with ESRD receive in-center treatments, three times a week for between three and four hours per treatment, or approximately nine to 12 hours per week. By contrast, home dialysis makes it possible to dialyze for longer periods at a slower, gentler pace, more closely approximating natural kidney function. Frequent, slower home dialysis is also less stressful on the patient’s heart, lowering the risk of premature death, and increasing the likelihood of survival to transplant, if that is the patient’s treatment goal. In addition, home dialyzors require fewer medications and fewer hospital services. Finally, although there are upfront costs to training a patient to dialyze at home, once the patient has been trained, the costs per treatment are lower. (continued page 4)
Treating more frequently allowed me to focus on my music career and find a transplant donor instead of focusing on my daily battle with kidney failure. I was also able to improve my health and lost more than 100 pounds. Prior to then, I was not considered healthy enough to sustain a new kidney, but with the improvement of my health, I became a candidate for a kidney transplant.

In 2010, my brother was identified as a perfect match and I underwent kidney transplant surgery. Today, I’m married to my childhood sweetheart and have a son, 3 and a daughter, 2. Looking back, I can’t believe I wasn’t educated about all of my treatment options. When I first heard my diagnosis, I was so scared and confused I didn’t even understand what was happening to me. I knew I needed dialysis but I was never made aware that I had more options than just in-center. I found HHD because I wasn’t willing to settle.

Unfortunately, many patients don’t realize there are other treatments that could drastically improve their health and lifestyle. Little do they know, another therapy option could be much better suited to their lives. Most patients don’t have a job that requires them to travel to 40 cities, but I like to tell them to find their own 40-city tour and live their lives to the fullest.

Home Hemodialysis Saved My Career and Life
By David Rush

In 2007, my music career was taking off. I had just been signed to Pitbull’s record label, Mr. 305 Inc., and released my first two singles. Unfortunately, it was around the same time I began having serious health issues. I felt tired all the time and began gaining weight. It was that same year I was diagnosed with kidney failure. At 24 years old, I found out I would need to be on dialysis to stay alive unless I received a kidney transplant.

It seemed in-center dialysis was my only option, and I hated it. It was an extremely depressing experience. An older patient who treated me like family didn’t show up one day and I heard she had died. Soon after that, another patient who sat across from me went to the hospital and never came back. I thought this was just how my life was going to go. I began to feel like some of the 70-year-old patients in the chairs next to me. I thought, “This can’t be what is left of my life.” Luckily, it wasn’t.

After a year of restrictive in-center dialysis treatment, I was offered the once-in-a-lifetime opportunity to travel on a 40-city tour with Pitbull. While receiving in-center treatment, traveling was impossible but I just couldn’t imagine missing out on this opportunity. It wasn’t until my manager Manny looked online for home dialysis that I found out about portable home hemodialysis (HHD). It was the first glimpse of hope I had in over a year.

We quickly found a center to train me and I went on the road. I performed 50 shows and brought the dialysis machine with me on the bus tour.

Stop by and see HDU in San Diego at ASN Kidney Week
Booth Number 745
Nov. 5-7 2015

Look for the HDU Newsletter quarterly, on our website or in your email.
Send us your story and you might be featured as a Home Dialyzor Success Story in a future newsletter.
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HDU’s Advisory Board — Who They Are

Mollie Perry, RDA Co-Founder and President of VidaFuel, LLC.

Mollie Perry is Co-founder and President of VidaFuel, LLC, the first food company solely dedicated to creating foods safe for those with Chronic Kidney Disease and on Dialysis. In addition to her Registered Dietitian designation, Ms. Perry holds a Master of Science in Nutrition and Exercise Physiology and she is an American College of Sports Medicine Certified Personal Trainer. Ms. Perry’s spectrum of practice has spanned across all disease types from diabetes to kidney disease.

The Honorable Karen Thurman, Advocacy and Policy

Hon. Karen Thurman has a personal interest in kidney disease and treatment, including dialysis. Two in her family suffer from Polycystic Kidney Disease (PKD). As a Member of Congress from Florida from 1993-2003, Karen Thurman worked for many kidney issues, especially in the area of immunosuppressive drugs for kidney transplant patients. She was also a member of the board of directors of NKF for 6 years. A partner in TG&C Group, LLC, Karen Thurman continues her work on behalf of kidney disease patients by representing the PKD Foundation.

Eric Weinhandl, Research and Education

Eric is an epidemiologist, finishing his PhD in the field earlier in 2015, after having finished a master's degree in biostatistics in 2004. His first project was a study of death rates in peritoneal dialysis and matched in-center hemodialysis patients. Since then, he has worked on many interesting projects and written papers for medical journals, including the advent of Medicare Part D, which has brought better insight into medication use among dialysis patients than ever before. He is also an adjunct assistant professor in the College of Pharmacy at the University of Minnesota.

Ellen Griffith Cohen, Policy

Ellen Griffith Cohen retired in August 2012, after 11 years as a press officer in the national office of the Centers for Medicare & Medicaid Services. Her experience with CMS has been invaluable to the HDU Policy committee, helping to write and edit comments to CMS and GAO. She is currently pre-dialysis and pre-transplant. She is planning to undergo a living donor transplant in January.

Celeste Castillo Lee, Education

Celeste Castillo Lee is a 34 year patient of ESRD currently on in-center hemodialysis. She is a faculty for the Institute for Patient and Family-Centered Care and a patient advisor in non-profit health organizations, governmental agencies, research projects, peer mentor and advocate nationally, and internationally. Including a Board Member, and Chair of the Patient & Family Partnership Council for the Kidney Health Initiative, a public/private partnership with the FDA and the American Society of Nephrology, a member of the Phase I National Patient Advisory Council for PCORnet, and a member of the steering committee for the Vasculitis Patient-Powered Research Network (V-PPRN).
Barriers to Increasing Use of Home Dialysis

Lack of Information about Home Therapies

Although the Social Security Act specifies that Congress intends for any patient who is a suitable candidate for home dialysis to be so treated, and Medicare requires centers to educate patients about all treatment options, too many patients are unaware that they can dialyze at home. According to the most recent information:

- Only 12% of patients report being educated about HHD.
- Only 24% of centers are certified to offer home hemodialysis (HHD and not all centers that are certified to offer HHD actually do so.), This means that access to HHD may depend on such arbitrary factors as where the patient lives.
- Rural areas are traditionally underserved, and, according to the Medicare Payment Advisory Commission’s most recent report, the number of rural centers is decreasing.
- As a result, fewer than 2% of patients with ESRD are currently doing HHD, although many nephrologists believe that a much higher percentage of patients would be good candidates for HHD and, according to surveys of nephrologists, most would choose home dialysis for themselves or family members.

Moreover, efforts to improve patient awareness of treatment choices too often ignore HHD as a treatment option. For example, in January 2013, the Patient-Centered Outcomes Research Institute (PCORI)* contracted with Arbor Research to create a decision tool to help dialysis patients make an informed decision about RRT. In preparing the study, entitled “Empowering Patients on Choices for Renal Replacement Therapy” (EPOCH-RRT) Study,” Arbor looked at in-center treatment and PD, but did not consider HHD. HDU strongly urges that omitting HHD violates PCORI’s mandate, and its stated mission to provide patients with “information about which approaches to care might work best, given their particular concerns, circumstances, and preferences.”

The Partner Requirement

The FDA clearances for dialysis machines to be used in the home require that the patient have a care partner who is also trained to operate the equipment and who can assist in emergencies. This requirement prevents people who live alone (or whose care partner is temporarily absent) from doing HHD, and may place an undue burden on the family unit. Surveys consistently show that the care partner requirement is the #1 barrier to implementing home hemodialysis. HDU believes that a dialyzor should be able to choose to perform HHD without a care partner. The center should discuss with the patient the risks of dialyzing alone, assess the dialyzor’s ability to perform his or her own treatments without assistance, and discuss alternate safety precautions available to the patient if the patient chooses to forego having a care partner.

How YOU can HELP us.

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Home Dialyzors United depends on tax exempt donation to continue the education, support and advocacy of home dialysis. We can't do it without your help. Donations can be made on our website via PayPal.

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JOIN

HDU Membership is FREE

Home Dialyzors United (HDU), a 501(c)(3) nonprofit, is the only dialysis patient organization dedicated to home dialysis. Our membership is inclusive of dialyzors, care partners, nurses, nephrologists, renal professionals and others. Our mission is to educate, support and advocate for home dialysis. Membership form is available on our website. Sign up today!

HomeDialyzorsUnited.org