

# HDU NEWS

***Working for you. Our Day, Our Way***

## ***INSPIRE***

As dialysis patients, care partners, nurses, nephrologists, renal professionals, and supporters and friends of those with chronic kidney failure we encourage our members, both veterans of dialysis and newcomers to treatment, and the community that supports them.

## ***INFORM***

We desire an extraordinary quality of life for all dialyzors. The dialyzor comes first and care must be patient centered. We believe those on dialysis deserve to live a "new normal" life, whether that be working, volunteering, or traveling, and that they should be able to be full participants in family and community life.

## ***ADVOCATE***

We advocate proactively for issues impacting the home dialysis community. We will stand up for what is best for the patients and don't hesitate to push buttons or stretch the envelope in order to ensure the best health care for those with kidney disease and chronic kidney failure.



Home Dialyzors United, a 501(c)(3) non-profit patient organization, is the only dialysis patient organization dedicated to the home dialysis community.

Our Mission:

*To inspire, inform, and advocate for an extraordinary quality of life for the home dialyzor community.*



## Access Denied

by Don Mason

I still remember March 3, 2012. It was the day my doctor told me I had kidney failure and that I needed to start dialysis immediately. I didn't even know what dialysis was. I do not remember being given any options except that if I didn't receive dialysis treatment, I would die.

After six months of receiving in-center dialysis, I expected I would get used to it and start to feel better. But none of that happened. Instead I was tired all the time, constantly struggling to catch my breath and feeling worse. I remember having to sit on the bottom step of my building for 30 minutes before I could even begin to go up to my apartment on the third floor. I became very depressed with my life. I hadn't seen my grandchildren for over eight months because I didn't want them to see me so weak. I missed celebrating holidays with my family just because I

After about a year in-center, one day I went online and started researching more about dialysis. All of a sudden I came across a video of a young woman talking about how she did her own treatments at home, eventually getting her life back and doing the things she used to do. I remember jumping out of my seat thinking, "This is it, this is what I want!"

I started training with home hemodialysis in April 2013. I went to a training class for four weeks. The nurses spent all day by my side, teaching me all I needed to know to do my own treatments safely at home. There was a lot to learn, but by the end of the training, I had already noticed the difference. When I got home, I could quickly and easily walk up the stairs. I snapped out of feeling like I was in a really dark place. My thoughts were much clearer, my recovery time was faster and I was in control of my treatment. My family recognized I came "back to life" and I felt that my goals were attainable again.

More patients should have the chance to experience improvements in care like I did with home hemodialysis. Unfortunately, many patients do not have the option to do home dialysis. Only about one in four centers offer home hemodialysis, in part because Medicare's payment for training patients to dialyze at home only covers a small fraction of what it costs providers to offer the service.

The Centers for Medicare and Medicaid Services (CMS) bases payment for training on only 1 ½ hours of additional RN time per treatment. I can tell you that when I was in-center, the nurse was with me only at the start and end of treatment but in home training, my nurse was with me throughout the day. Medicare needs to make their training payment fit the reality of the RN investment in training.

That is the only way patients will get fair access to home hemodialysis. Until that happens, it remains access denied.

Look for the HDU Newsletter every Quarter, online or in your email. Send us your story, to [ngedney@homedialyzorsunited.org](mailto:ngedney@homedialyzorsunited.org), and you might be featured as a Home Dialyzer Success Story in a future newsletter.

# HDU Who We Are

*At the Annual Board Meeting in February, 2015 the Home Dialyzors United Board welcomed new board members and voted on officers.*

*These members represent all facets of the dialysis community and are dedicated to working tirelessly for you.*



Denise Eilers, President

**President: Denise Eilers**, BSN, RN, was a care partner to her late husband for 25 years and a former Director of Nursing and Nursing Home Administrator. The last 16 years she has been the Coordinator of Health Occupations and a nursing instructor at United Township Area Career Center in East Moline, IL. Presently, Denise is an adjunct instructor at a local junior college. She has also been Vice President of HDU for several years, and head of the Advocacy, Policy and Education committee.

**Vice President: Nieltje Gedney** spent 20 years avoiding dialysis, and then found herself in the ER a year ago, crashing, and placed on emergency hemo. After starting home hemo, she felt great! Nieltje is no newcomer to advocacy work, just to dialysis, and is really enjoying her recent role as HDU's Vice President and working on the Policy and Advocacy Committee.

**Secretary: Amanda Wilson**, mother, nurse and dialyzer, on PD for a year and a half, transplant for ten, PD for another eight and four years on home hemodialysis. Originally from the UK, she has lived and dialyzed in many countries, before landing near Atlanta GA. She is doing a great job of keeping all the HDU meeting information on track, and keeping the Board informed. She also worked on the recent website conversion, and moderates the HDU Facebook group.

**Treasurer: Pat Colongione** was one of the original founders of Home Dialyzors United and was also the caregiver to her husband Ralph for 8 years. Sadly, Ralph has passed, but Pat carries on her advocacy in his honor. Besides being Treasurer to HDU, she works part time at a local college, and is a travel agent, often organizing trips and cruises for dialyzors, as well as travel for the HDU Board, as needed.

## Directors at Large

**Amy Staples** who recently joined our board was diagnosed with PKD at age 21. She is also the author of the blog Kidney Beans and Counting as well as the owner of Kidney BEANS a Facebook support group. The group focuses on offering love, support, and answers to the complex challenges of caring for and living with CKD or ESRD. We are delighted to have Amy and her talents helping us at HDU!

**Ben Rubeck** is currently on a leave of absence. We look forward to welcoming him back soon.

HDU is always looking for dedicated people who would like to contribute their talents to our efforts to improve the dialysis community. There are currently 2 Board Positions and a number of Committee openings available. Please submit a Board or Committee application ([link](http://homedialyzorsunited.org/hdu-membership-leadership-and-volunteer-opportunities)) for consideration to <http://homedialyzorsunited.org/hdu-membership-leadership-and-volunteer-opportunities> to apply.

## HDU is Working for YOU!

### Meetings with CMS, FDA, ASN, and Members of the Kidney Caucus

July 20, 2015

On July 22, 2015, representatives from the HDU Board met with CMS officials to discuss issues affecting renal and dialysis patients. Specifically, we planned to discuss payment and training for home hemo, as well as the availability of dialysis in the long term care setting. We developed a position paper which we are sharing with our members (<http://homedialyzorsunited.org/improving-patient-access-to-home-dialysis>), and may be reprinted as a handout.

In addition, various HDU Board members have attended the following events to represent the needs of home dialyzors: The National Association of Renal Administrators Policy Day on the Hill, May 19-20, 2015, Kidney Health Initiative, May 20 and August 14, 2015, ANNA Policy Day on the Hill June 20, 2015, , The Alliance for Home Dialysis Mini Summit, July 27, 2015, ASN Policy Day on the Hill September 10, 2015, IU "The Road Home, September 17-18, 2015. AAKP Annual Conference, September 27-28, 2015, and ASN's Kidney Week November 3-8, 2015.

### Press Release: HDU Urges CMS to Increase Payments for Home Hemo Training

August 26, 2015

Home Dialyzors United (HDU) today urged the Centers for Medicare & Medicaid Services (CMS) to increase payments for home hemodialysis training and to include measures that apply to dialysis center services to home dialysis patients. Although numerous studies have found that patients who use home dialysis, and particularly home hemodialysis, have better outcomes, and a better quality of life, only about 10 percent of Medicare patients with ESRD dialyze at home, and only 2 percent do home hemodialysis.

Among the barriers to home dialysis are lack of complete, unbiased education about dialysis treatment options, lack of access to dialysis centers that offer home dialysis, and payment incentives that favor traditional, in-center treatment over home dialysis. Find out more at <http://homedialyzorsunited.org/press-release-hdu-urges-cms-to-increase-payments-for-home-hemo-training>

## How YOU can HELP us.

### DONATE

Home Dialyzors United depends on your 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:

<http://homedialyzorsunited.org>

### SPONSOR

We want you to be an integral part of our advocacy efforts, since you provide a product or service to the renal community. By securing a sponsorship location on our home page your company you will familiarize the renal community with your products and services, increase your name recognition, and help establish your "brand" in this niche market as a supporter of the renal community. Visit our website for information.

<http://homedialyzorsunited.org>

or email

[ngedney@homedialyzorsunited.org](mailto:ngedney@homedialyzorsunited.org)

### 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!**

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