Kidney Konnections

A publication of the



The Bay Area Association of Kidney Patients is an all-volunteer, non-profit, 501(c)3 organization formed to educate and support Bay Area kidney patients. Visit us at

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The Significance of the Five Stages of Chronic Kidney Disease

Dr. Glenn W. Chertow was the featured speaker at our September 2013 Presentation entitled "The Stages of CKD: What do they mean and what should we do?" Glen W. Chertow, MD, MPH, is Professor of Medicine and Chief, Division of Nephrology at Stanford University School of Medicine. Dr. Chertow previously served with distinction on the faculties at Brigham and Women's Hospital, Harvard Medical

School and the University of California San Francisco (UCSF) and has published over 200 articles and received numerous honors and awards.

Dr. Chertow approached us like one of his medical school classes. He did not use prepared slides to illustrate his talk; rather he personally engaged the audience with questions and answers and thereby gained their rapt attention.

His first point was the terms "end stage kidney disease" and "kidney failure" have such a negative connotation that they should not be used. Over the years, many different terms for kidney disease evolved. in fact there were so many, that he and some colleagues wrote a paper entitled "Chronic Renal Confusion" in the late 1990's. Dr. Chertow feels that "Chronic Kidney Disease", or "CKD", is the preferred way to (Continued on page 2)



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The Launch of the "Ask the Expert" Series Leesa Yim

As announced in our Summer 2013 *Kidney Konnections* newsletter, BAAKP launched our "**Ask the Expert**", series presenting video sessions at our website featuring industry and medical professionals. These 30 minute to 1 hour-long live videos allow patients and caregivers to ask and then learn about various kidney related topics while in the comfort of their own home.

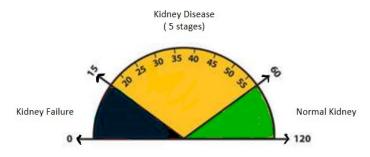
On August 4th, our very first live video session was entitled "**Ask A Nephrologist**" with guest speaker **Dr. Toby Gottheiner**, BAAKP's medical advisor and a practicing Nephrologist at Palo Alto Medical Foundation. In this very first video session, Dr. Gottheiner addressed the topic of "When Is the Right Time to Start on Dialysis?"

Dr. Gottheiner stated that there have been several studies indicating the patients who started on dialysis with lower GFR did just as well as those who started on dialysis with higher GFR. To determine the right time to start on dialysis, Dr. Gottheiner spoke about current recommendations by Kidney Disease Improving Global Outcomes (KDIGO) organization http://kdigo.org/home/ and addressed the risks and benefits of being on dialysis. Does it

(Continued Chronic Kidney Disease)

refer to kidney disease.

His second point was to describe the derivation, use and limitations of Glomerular Filtration Rate "GFR", used to define the five stages of kidney disease. The higher, the stage the less kidney function is present. He pointed out that GFR is the measure of serum creatinine filtering, which is only one of the many functions of the kidneys, so other factors must be considered for each individual. BUN could be measured and used in a similar way but it turned out to be a less reliable indicator of kidney function. The kidneys not only filter wastes and excess water from the blood, they are involved in biological functions which are just as important, such as the control of calcium levels, hemoglobin levels and blood pressure. All of these functions of the kidneys are very important and they may fail or they may continue working even in Stage 5. They do not necessarily coordinate with the filtering of serum creatinine, which is the basis for the GFR rating. He noted that high blood pressure could be both a cause and an effect of kidney disease; other major causes of kidney disease are diabetes and obesity. Dr. Chertow believes that our con-



Where is your kidney?

cept of kidney disease as "Stages 1, 2, 3, 4 & 5" as defined by the estimated GFR is misleading. The GFR formula is based on an equation that includes not only the serum creatinine measurement, but age, sex, and race of the individual. From a trial program, The National Kidney Foundation derived the five stages of kidney disease from a study of GFR test results from 1500 patients of whom 1200 were tested over a period of years. Most of the patients in this trial had advanced kidney disease so they had a high GFR levels at the start of the study. Thus, the results were skewed towards high GFR patients and are not as accurate for patients with low GFR levels. In addition, the equation used to calculate GFR is "population--based" so inevitably there will be errors when it is applied to an individual. He warned us to not get "hung up" on the stages of CKD based on estimated GFR, but to also take other aspects of the your health into consideration.

As a sidelight, he noted that this same trial showed a low protein diet had little benefit and ACE Inhibitors (Angiotensin-converting enzyme medications for high blood pressure) showed greater benefit for the kidney patient. This study also showed a blood pressure level of 140/90 was okay compared to "astronomically" high levels, and striving for a lower 120/70 was not required. Chertow listed the stages:

Stage 1: (90 or more GFR with other symptoms)

CKD patients he felt should not be considered to have serious kidney disease at this stage.

Stage 2: (60-89 GFR)

CKD and PKD patients he also felt should not be considered to have serious kidney disease, but other symptoms should be watched.

Stage 3: (30 to 59 GFR)

This is a broad range, he pointed out, and so you can have a broad range of symptoms. Patients do need to be followed by a **nephrologist**, especially if there is **blood or protein** in the urine or some other disease that could have damaged the kidneys. With proper care Stage 3, patients can retain adequate kidney function for decades. "If you are not feeling well it's probably something else", he said.

Stage 4: (15 to 29 GFR)

Patients often do have serious kidney disease and should be treated as such. He warned that you should be on the lookout for cardio/vascular complications. These patients are likely to progress to Stage 5.

Stage 5: (GFR of 15 or less)

Dr Chertow's advice is to be a strong advocate for yourself. If you feel badly, it could be the CKD or it may be some other associated disease. He feels you do not need dialysis just on the strength of your estimated GFR alone; Stage 5 does not automatically require dialysis without other symptoms. You could have many or just a few other symptoms with a GFR of 15. The decision for dialysis or transplant should be

Thank you Dr. Chertow for the generous donation of your time and support for kidney patients. □

Contact Information: Glenn Chertow, MD, MPH: Stanford Hospital and Clinics, (650) 725-4738, gchertow@stanford.edu



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"It's Great to Have my Life Back"

BAAKP plays large part in Patient's Treatment, Twice!

Kirk (left) and Kris (right)

"It's great to have my life back", said **Kris Washburn**, a Bay Area Association of Kidney Patients' member since 2010.

His story began at the age of 18, when, at a routine physical, his doctors discovered protein in his urine; this was dismissed because he had just completed a strenuous run, which can sometimes cause a protein "leak". Later on, protein was again discovered in his urine, but the red herring this time was that he had an active infection going on. Again, when he

was 25, the doctors passed off a blood pressure of 180/100. Eventually he visited a clinic because his right eye was blurry; they discovered a blood pressure of 210/120 and a creatinine of 3.2; he was immediately hospitalized for "acute" kidney disease and released to find a Nephrologist when his creatinine decreased to 2.7.

It took 2 months after his discharge from the hospital, for Kris to work through various insurance problems to get an appointment with a

Nephrologist. Finally, a biopsy was performed and he was diagnosed with "classic" IGA Nephropathy. That was in May of 2010; he also learned that he had only 23% kidney function.

At that time, Kris was working in San Francisco as a bartender and he said it was "hard to be a 'happy' bartender" with all of the dialysis he needed. He started CAPD (Continuous Ambulatory Peritoneal Dialysis) with some residual kidney function, performing exchanges 4 times a day.

One month later, as his kidney function rapidly decreased, he added the night cycler. This added 4 or 5 additional cycles per night. Combined day and night dialysis totaled 7 cycles per 24 hours, "a lot more dialysis than I anticipated it to be", he said. His creatinine never reached the desired levels, and when he finally went for a transplant, his creatinine was at 20!

again discovered in his urine, but the red herring this time

Until he could get a transplant, Kris was doing all he
was that he had an active infection going on. Again, when he
could do to learn as much as possible about kidney disease.

Introduced to BAAKP by his mom Kristine Newman, Kris met one of the speakers at a BAAKP Educational Presentation. This was a very significant moment! Mr. **Chris Douglas**, a disabilities rights attorney with the Legal Aid Society of San Mateo County, spoke in March of 2011 along with a panel of experts about **Financial and Insurance Questions**. Mr.

Douglas felt he could help Kris with the burdensome cost of his medical care at that time. Kris was re-

ceiving \$1400 a month in state disability and his copay for medical care was \$1200 a month: a financial impossibility! Mr. Douglas helped him reduce that co-pay to \$20 per month, leaving money for food and lodging.

Luck Intervenes Again! Or, was it being in the right place at the right time? In January 2012, Dr. Stephen Busque of Stanford Kidney Transplant was a speaker at another **BAAKP Educational Presentation**. Kris was in the audience and was immediately attracted to Dr. Busques' ex-

(Continued on page 4)

Season's Greetings!

From your Board of Directors



Row 1: Tien Tracy Tarkul, Ben Lee, Vivian-Jan Tarkul, Walt Umbach, Catherine Enciso, Robert Furniss, Willie Mackay Row 2: Patrick Barron, Mallory Ignacio, Linda Umbach, Mila Kelman, Leesa Yim, Marcus Wong. (Missing: Dhiman Barman, Phil Wyche)

perimental program called "**Tolerance Induction**". (see *Kidney Konnections* Volume 5, Issue 2) Dr. Busque's study involves using a related live kidney donor with the goal of having the transplant recipient eventually weaned from any and all transplant medications.

At first, the going was rough for Kris and his family. The experimental study requires the living donor to be a "perfect match". Disappointingly, his mother and one brother only matched 3 out of the 6 antigens; Dr. Busque's procedure requires a 6 out of 6 match. Still recovering from this disappointing news and unbeknownst to Kris, a second brother, Kirk, who lives in Colorado had himself tested as a donor. Kris' fortunes turned when Kirk called and informed Kris he was a "perfect match" with 6 out of 6 antigens.

On July 9, 2012, the kidney transplant surgery took place, but only after months of preparation by both brothers. Kirk flew in from Colorado 6 weeks prior to surgery, received erythropoietin shots for 3 days in a row and on the 5th day had his blood drawn by Stanford. Six weeks later, on a Monday, the surgery took place with Kirk's kidney removed laproscopically, and Kris receiving Kirk's kidney. Kris then received radiation to certain lymph nodes on Tuesday, Wednes-

day, Thursday and Friday (this was after having the transplant on Monday!). Kris still has the tattoos that mark the areas of radiation on his chest, abdomen and neck. "I didn't feel a thing", Kris states of the radiation treatments, and he was discharged to go home on Friday, only 5 days after the surgery. Kris returned as an outpatient the following week for more radiation every day Monday through Friday, with a double dose on Friday. As a final step, Kris then received Kirk's **stem cells** and **T cells**, which had been collected from Kirk's blood donation 6 weeks earlier.

Both of the brothers are doing well. Kris Washburn's journey to a kidney transplant has been a credit to Kris, his brother Kirk and the rest of their family, plus the skill and ingenuity of the physicians involved. He is finishing his senior year at San Jose State with a degree in Finance, and is not taking any transplant medications at all! At one point, Kris was taking 35 pills a day, including cyclosporine (Gengraft). Now he is completely off all medications, including "transplant meds". And he does indeed have his life back!

This newsletter is not intended to take the place of personal medical advice, which should be obtained directly from your Doctor.

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- •Honor those who have donated organs or tissues.
- •Honor the families of organ donors.



Just released! **Donate Life California** is producing this gorgeous new plate. Order this special plate for your vehicle (auto, truck, trailer and motorcycle), by going to the website at www.pinkdotplate.org. It can be personalized or consist of random

Other Kidney Resources— Check our website at www.baakp.org for more!

American Association of Kidney Patients AAKP

2701 N. Rocky Point Dr. Suite 150 Tampa, Florida 33607 (800) 749-2257

www.aakp.org

San Francisco Polycystic Kidney Foundation

numbers. In any form, it will speak to those who see you in your car!

1-800-PKDCURE

www.pkdcure.org/ sanfranciscochapter

sanfranciscochapter@pkdcure.org

Transplant Recipients International Organization TRIO

2nd Thursday of each month 7:30 pm. El Camino Hospital, Conference Room G 2500 Grant Road, Mountain View, CA (408) 353-2169 www.bayareatrio.org

The National Kidney Foundation

131 Steuart St Ste 425 San Francisco, CA 94105 www.kidneynca.org 888-427-5653

www.kidney.org

(Continued Ask the Expert)

make sense for everyone to eventually be on dialysis? If so, when? Should we depend solely on our GFR numbers? Later in the video, Dr. Gottheiner answered these and other questions from our patients. To hear the answers to these questions and to see the full video session with Dr. Gottheiner please visit http://baakp.org/video/baakp-ask-the-nephrologist.



We continued our video webinars with a session on Aug 18th entitled "Ask a Renal Dietitian" with Marianne Wolfe-Hutton, a renal dietitian and certified diabetes educator with over 21 years' experience. During the first part of the video, Marianne talked about "Managing the Diabetic-Kidney Diet". She began with startling statistics, noting that 1 in 9 people have CKD (Chronic Kidney Disease) and 1 in 3 people have diabetes. In 2007, diabetes was cause of 54% of new cases of end stage renal disease.

Marianne reminded us CKD has a huge impact on minority populations: African Americans, as well as Native Americans, Hispanic Americans, and Asian-Americans. All have a disproportionate incidence of CKD and diabetes. Early detection of kidney disease both in diabetics and non-diabetics, plus the use of the right food plan can slow the progression of your kidney disease. Therefore, working with both your Nephrologist and your Renal Dietitian is important. Marianne then noted the importance of sodium, phosphorous, protein, carbohydrate, and potassium in one's diet.

Hearing about what we have to limit in our diet can be daunting and overwhelming and Marianne and other renal dietitians understand that. People often ask: "What can I eat?" and the answer is "it all depends". As long as you have a renal dietitian on your team, they can come up with the food plan that is right for you.



Marianne also addressed the question of limiting protein intake in our video. For more detailed information on diabetickidney diet and answers to these and other patients' questions please visit our website. By clicking here http://baakp.org/video/baakp-ask-a-renal-dietician, you can attend Marianne Hutton's webinar on diet.

On November 2nd, BAAKP had guest speaker **Dori**Schatell to talk about "The Importance of Choosing The
Right Dialysis For Youl". Dori, along with Nephrologist Dr.
John Agar, have written a book entitled, "Help, I Need Dialysis!" with a varied audience in mind. The book is good for people whose kidneys are failing and need to choose a dialysis option, for those who are already on dialysis but not quite happy with their current option, and, finally, professionals who are looking to better educate their patients and families.

Dori described different types of kidney replacement therapies, standard in-center hemodialysis, peritoneal dialysis (continuous ambulatory PD, continuous cycling PD), short daily hemodialysis, and nocturnal hemodialysis (in center and at home).

One needs to look at his/her lifestyle when picking the right dialysis option. One also needs to consider food and fluid intake for dialysis, but the restriction varies on different therapies. For example, the nocturnal hemodialysis patients might not need to take phosphorus binders and may not have any fluid intake limits.

Dori also talked about "work friendly" consideration for different treatment options. Although, nocturnal hemodialysis has many benefits, ease of travel is not one of it's benefits. Nocturnal hemodialysis is often referred to it as extended hemodialysis because FDA has not approved any specific machines for nocturnal use, even though there are machines out there being used for nocturnal hemodialysis.

A patient needs to be aware of diet differences for each type of therapy in case the patient switches therapy for a reason. For instance, a patient normally doing a nocturnal therapy at home might need to do a standard in center hemodialysis when traveling:; with that change, the patient needs to watch his/her potassium intake.

Visit www.homedialysis.org to see list of dialysis centers in US. To hear more about different dialysis treatments and learn how you will be able to get better results from each dialysis treatment please visit our website at www.baakp.org. You can also attend this webinar with Dori Schatell by clicking http://baakp.org/video/baakp-presents-the-importance-of-choosing-the-right-dialysis-fi-1.



Coming soon, BAAKP will be hosting another web interview with Marcelo Espiritu from Sourcewise, who will be discussing CKD Medicare coverage with the Affordable Care Act on Dec 1, 2013. Please join us online at www.baakp.org.

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Holiday Eating on a Renal Diet

Mathea Ford, RD/LD

When you are making your holiday plans, you can stick to your necessary restrictions and have a great time! Want to know how? Keep reading, and I am going to give you some great ideas about simple adjustments to make your day easier.

While most of the time it already feels difficult to follow a renal diet, on certain days of the year it feels like more of a burden because we plan those days around eating. You are probably wondering what to eat from the table instead of just celery and carrots.

Never fear, let me make your day a little easier.

WHAT TO START WITH

A meal plan or pattern can keep your day from getting out of hand. When you know what you are allowed based on your plan, you can pick from the list and have a good meal without compromise. Some of the foods are better than others to choose when you make your plate.

If the main course is ham, it is best to eat just a small amount because of the sodium. Unless the cook went out of his or her way to buy a low sodium ham, you can bet it's really high. Make other choices for your plate instead of ham.

Gravy is so easy to make from scratch, yet many people use the package. The packaged gravy is high in sodium, so you should try to convince the host to make it with a little flour and the pan drippings (called a "roux"). Offer to help and bring a healthy recipe for it – your goal is to lower the sodium as much as possible in your meal for the day. Watch out and don't use too much of the pan drippings because they do add a lot of fat to the meal. Cranberry sauce is something you can eat – it's low in potassium and phosphorus and can add a little sweetness to your meal if you don't eat the gravy.

WHAT ABOUT THE REST OF THE MEAL?

While side dishes vary around the country, you can look at eating more of the green beans and carrots and less of the sweet potatoes. Eat a good portion of the green beans and then a small portion of the sweet potatoes. Most of the time, just a taste is enough. And if it's not, then leave it off your plate.

Stuffing is a great part of the meal for kidney patients, unless you are a diabetic. If you are a diabetic, you need to count it as part of your carbohydrate for the day. But otherwise, making the stuffing from scratch doesn't take a lot of work and you can have a yummy side dish (with some of that great homemade gravy). If you are in charge of the meal, see about making it from scratch and eliminating the seasonings that contain salt. If you want to add flavor, add celery, mushrooms and carrots – they are low potassium. And low sodium broth or stock to decrease the added salt. If you eat the stuffing, skip the breads and rolls. It's easy to overeat – and almost everything has sodium.

For the other meal of your day, you can have a light turkey sandwich. Otherwise, think about another bowl of cereal or a Recipe

Apple Cranberry Stuffing

A tasty alternative to regular stuffing, and low in sodium too! Makes 10 servings

3 cups soft, stale bread crumbs
2 Tbsp unsalted margarine, melted
1/2 cup diced raw cranberries
1/4 cup chopped walnuts
1 cup diced, peeled tart apples
1/4 cup raisins

1/4 tsp poultry seasoning

1/4 cup apple juice

- 1. Preheat oven to 350'F. Combine all ingredients and toss lightly for the ingredients to mix. Using a 1 1/2 quart casserole dish, sprayed with pan release spray, add the mixture.
- 2. Bake the mixture for approximately 30 minutes, and divide into 10 servings. Serve hot.

Serving is 1/2 cup

Nutritional Analysis: Protein: 1.8 grams Fat: 5 grams

Carbohydrates: 13 grams Calories: 166 calories

Sodium: 7 ma

Potassium: 85 milligrams Phosphorus: 30 milligrams

Great for Pre-dialysis, dialysis, or renal diabetic 1/2 cup—1 low potassium fruit and 1/2 starch

Diabetic—1/2 cup—1 low potassium fruit and 1 fat

small hamburger. Eat that with low potassium vegetables and you should have a great meal. Remember that the day is meant to be spent together with others so most of all, enjoy your company on that day.



Mathea Ford is a registered dietitian and **CEO** of **Renal Diet HQ**, an online website that is on a mission to be the most valued resource on kidney disease that people can use to improve their health. Mathea also has several books about kidney disease which can be located on Amazon. Please visit her at her blog to learn more at www.renaldiethq.com.

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Welcome to our New Board Member

Mallory Ignacio was born and raised in Hawaii. She completed her undergraduate studies at the University of Hawaii at Manoa and later went on to the University of the Pacific where she earned a Doctor of Pharmacy

degree. During her graduate education Mallory participated in a variety of professional organizations and was a founding board member and Vice President of Pro-

fessional Affairs for the UOP student division of the American Society of Consultant Pharmacists. Mallory has early experience in retail pharmacy management and currently works as a pharmacist at Medical Plaza Pharmacy, an independent Bay Area pharmacy specializing in HIV and solid organ transplant immunosuppressive medica-

tions. She is the newest board member for the Bay Area Association of Kidney Patients. Given her constant exposure to both pre and post kidney trans-

plant patients, Mallory's goal is to connect with and serve those suffering from kidney disease. \square

Please donate every time you use Amazon.com for your purchases. Simply go to www.amazon.baakp.org - it will take you to your usual personal page, and BAAKP will get a small percentage of your purchase (at no cost to you).

We thank you in advance!

Thank You to Our Speakers & Sponsors For our Sept. 22, 2013 Presentation!

The Palo Alto Medical Foundation for use of their facilities.

Our Sponsor:



Our Speakers:

Dr. Glenn Chertow, MD, MPH: Stanford Hospital and Clinics, (650) 725-4738, gchertow@stanford.edu

Dr. Nancy Powers, Ph.D. Health & Behavior Consultant (415) 785-8600, npowersphd@att.com

Our door prize sponsor: Renal Diet HQ

We Need Your Help!

Did you know? Recent studies¹ show that kidney disease is projected to occur in 59% of Americans during their lifetime. Kidney patients and their supporters need information about chronic kidney disease, dialysis, and transplant.

1. Grams et al. Am J Kidney Dis 62(2):245-252

We have undertaken a Fundraising Campaign to raise \$26,400 to

Educate and Support San Francisco Bay Area Kidney Patients

BAAKP provides the following **FREE** services:

- Educational Presentations throughout the year
- Support Group Meetings on the Peninsula and in the East Bay
- Newsletters to over 1500 people
- An online hub for kidney disease, <u>www.baakp.org</u>, uniting kidney patients and their supporters and providing newsletters, videos, webinars

Until December 31st, all donations are matched 1:1 by our Partners:









Every little bit helps — send your tax-deductible contribution, no matter how small, by $\bf Dec.~31st:$

BAAKP

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Please visit our website at www.baakp.org to make a donation, see back issues of our newsletters, and view videos of our past meetings. Your help is greatly appreciated!

Educating and Supporting Bay Area Kidney Patients

SAVE THESE DATES!

Palo Alto Medical Foundation, 3th floor 795 El Camino Real, Palo Alto, CA

Educational Events (1-4 pm)

- **January 26, 2014**
- May 18, 2014

Support Group Meetings (1-3 pm)

- February 23, 2014
- March 23, 2014
- **April 27, 2014**

East Bay Support Meeting (1-3pm)

Alta Bates Summit Medical Center 400 Hawthorne Ave., Oakland, CA (BART station: MacArthur)

- **January 12, 2014**
- February 9, 2014 March 9, 2014 April 6, 2014

Board of Directors' Meetings 1st Tuesday of the month At 6:00 pm

If you would like to join us in the leadership of this group, we would love to have your help. info@baakp.org (650) 323-2225

January 26, 2014 Educational Presentation:

Updates on the Artificial Kidney Project and The ACA (Affordable Care Act)

At the January 26, 2014, Educational Presentation, the Bay Area Association of Kidney Patients will feature several speakers. Shuvo Roy, PhD, University of California, San Francisco Biomedical Microdevices Laboratory, will be updating our attendees on the The Kidney Project: Status and Plans for the Implantable Artificial Kidney.



Also speaking will be Marcelo Espiritu, from Sourcewise, formerly the Santa Clara County Council on Aging, Silicon Valley. As representative from HICAP (Health Insurance Counseling and Advocacy Program), Mr. Espiritu will be bringing an **Update on Health Insurance Cover**age of CKD and how kidney patients will be affected by the new ACA.



Don't miss this **FREE** event on **Sunday, January 26, 2014**, from 1 to 4 pm at the Palo Alto Medical Foundation, 795 El Camino Real, 3rd floor conference room, Palo Alto, CA 94301. There will be ample time for social interaction and patient support. Refreshments will be served! Door Prizes Too! To reserve your seat, please go to the website at www.baakp.org or call 650-323-2225.

This event is generously sponsored by providers of the home hemodialysis alternative.

