ESRD NCC NPFE-LAN Patient Summit

Going for the Gold: Overcoming Obstacles

Day 2

September 25, 2024

ESRD = End Stage Renal Disease
NCC = National Coordinating Center
NPFE = National patient and Family Engagement
LAN = Learning and Action Network

Meeting Logistics

- Call is being recorded.
- All lines have been muted upon entry to the meeting.
- Everyone is encouraged to use the chat feature (located in the bottom right corner of your screen) for submitting questions or comments.
- Let's practice! Please type your first name and where you are from in the chat box.

Social Media

- **Instagram**
@ESRD_NCC

- **Facebook**
@ESRD.NCC

- **X**
@ESRDNCC

Share your Patient Summit experience on social media!

- Use event hashtags on Instagram, X, and Facebook.
  - **#ESRDChamp**
  - **#TopOfThePodium**
- Tag the NCC's account so we can repost your content.

Agenda

Time	Topic	Presenter
12:00 p.m. ET	Welcome and Introductions	Centers for Medicare and Medicaid Services (CMS)
12:15–1:15 p.m. ET	Beyond the Podium: Cooking Strategies for Kidney Disease	Chef Duane Sunwold
1:15–2:15 p.m. ET	Home Dialysis- Addressing Body Image	Michelle Prager, LSW Heather Owens, RN Shannon Plaine, RN Dana Phlegar, Educator Bob McDonagh
2:15–2:30 p.m. ET	Break	
2:30–3:30 p.m. ET	Tennessee Kidney Foundation	Heather Corum Powell Dr.Jacfranz Guiteau Jonathan Trees
3:30–3:45 p.m. ET	Closing Remarks	ESRD NCC

CMS Welcome

CDR Daniel Thompson, MSN, COR, PFE-SME
Health Insurance Specialist | Division of Kidney Health
Center for Clinical Standards and Quality (CCSQ)
Centers for Medicare & Medicaid Services

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Overcoming Obstacles

Beyond the Podium

Chef Duane Sunwold

NPFE-LAN=National Patient and Family Engagement (NPFE) Learning and Action Network (LAN)

Beyond the Podium:

Cooking Strategies for Kidney Disease

Disclaimer

- I have no affiliation with any of the companies and products in this presentation.
- This is not medical advice. Consult with your care team before making any changes.

WASHINGTON DRIVER LICENSE

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ISSUE DATE 08-16-2001
DOB [redacted]

Duane Sunwold

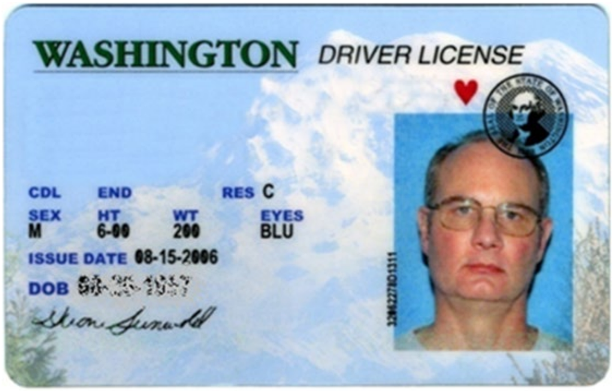

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Image Source: Duane Sunwold

Chef Duane’s Kidney Journey

- Before a plant-based diet
  - 2001
  - Creatinine >4.7
  - Micro Albumin >12 grams
  - Lowest eGFR 13

- After a plant-based diet
  - 2006
  - Creatinine 1.1 (today 0.8)
  - Micro Albumin 14 mg (today 8 mg)
  - eGFR 98

eGFR = estimated glomerular filtration rate

How To Add Flavor

- Herbs and Spices
- Acids
- Coconut Aminos

What to Consider

Herbs and Spices

- Smell the herb or spice
- Fresh or dried
  - 3 to 1, (3 teaspoons fresh = 1 teaspoon dried)
- Create your own herb blend
- Heating herbs and spices brings out their flavor
- Ongoing research is identifying health benefits
  - ○ Example, oregano is very high in antioxidants

Soy Sauce vs. Coconut Aminos

- Soy Sauce and lite soy sauce
  - High in sodium
- Coconut Aminos
  - Certain brands – low in sodium

Animal vs. Plant Protein

Amino Acids

- Essential amino
- Non-essential

Animal Protein

- Substantial amounts of essential amino acids
- Acidic
- Less fiber

Plant Protein

- Essential amino acids
- Alkaline
- More fiber

Plant Protein Sources

Legumes

- Beans
- Chickpeas
- Lentils
- Soy

Nuts and Seeds

- Almonds
- Cashews
- Peanuts
- Sunflower
- Chia

Veggies

- Mushrooms
- Peas
- Broccoli

Grains

- Quinoa
- Wheat Gluten (Check with your medical team)

The High Hurdle – Diabetic Kidney Disease Diets

- Colored vegetables
  - Broccoli
  - Red, green, yellow peppers
  - Peas
- Complex carbohydrates - Whole grains
- Healthy fats
  - Olive oil
  - Avocado

Vegan African Peanut Stew

https://www.kidney.org/recipes/vegan-african-stew

Mediterranean Chickpea Salad

https://youtu.be/FXfrg6Yvw1A?si=hdebuFC3Z7ZldaIU

Spicy Roasted Cauliflower Tacos with Cilantro Lime Crema

https://youtu.be/coxwAPmbrSg?si=qLp6mlm8X5m8-pPm

NATIONAL KIDNEY FOUNDATION®

Image Source: National Kidney Foundation

Resources

- Recipes
  - www.kidney.org
  - www.pskc.org
- Spices
  - www.spiceology.com
  - www.penzys.com
  - www.mccormick.com
  - www.sauers.com/pages/spicehunter-1

Questions

Contact Information

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Let Us Hear From You

Questions and Answers

NPFE-LAN Patient Summit

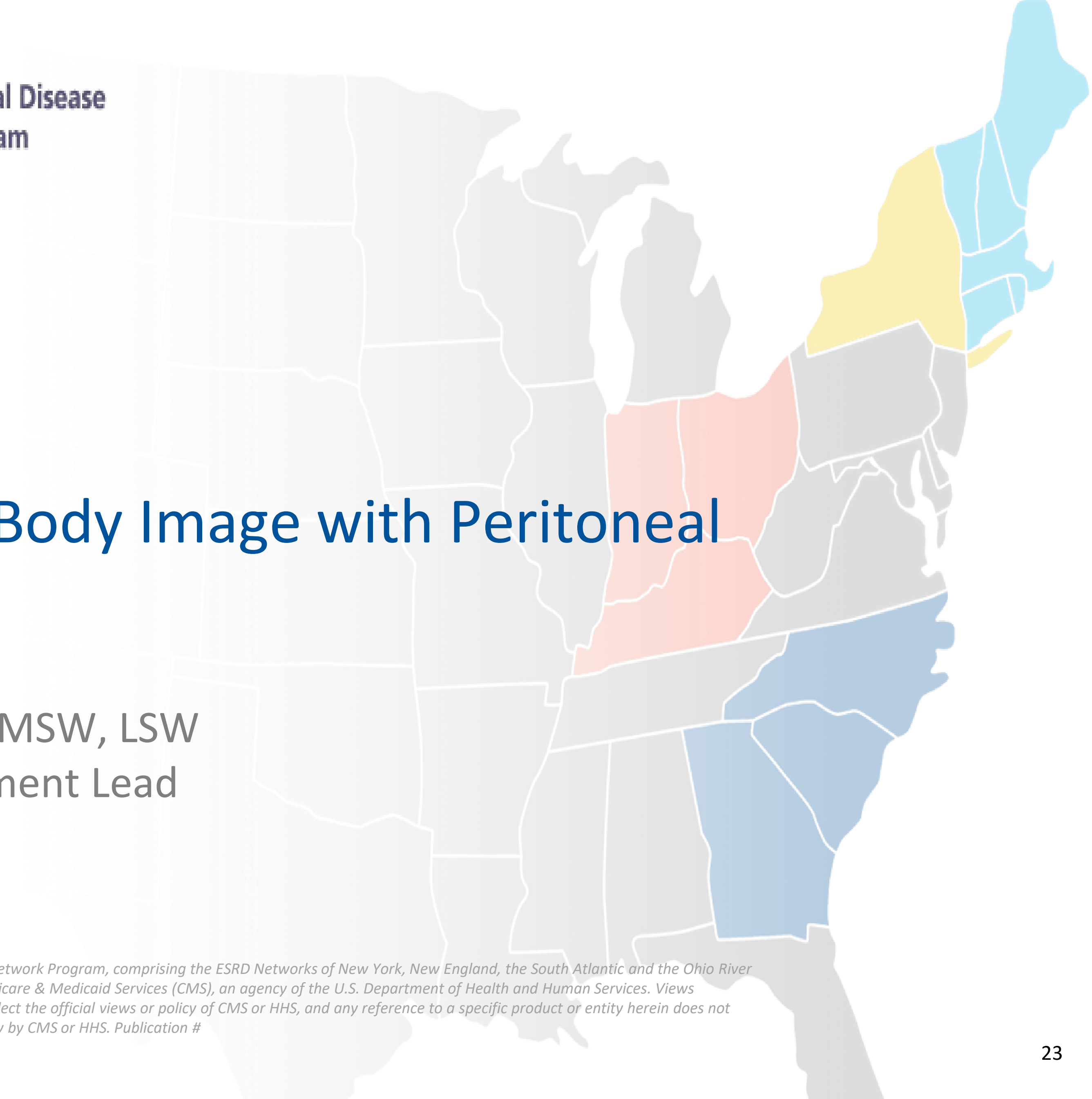
Going for the Gold:
Overcoming Obstacles

Peritoneal Dialysis and Body Image

Michelle Prager, MSW, LSW
Heather Owens, RN
Shannon Plaine, RN
Dana Phlegar, Educator
Bob McDonagh

NPFE-LAN=National Patient and Family Engagement (NPFE) Learning and Action Network (LAN)

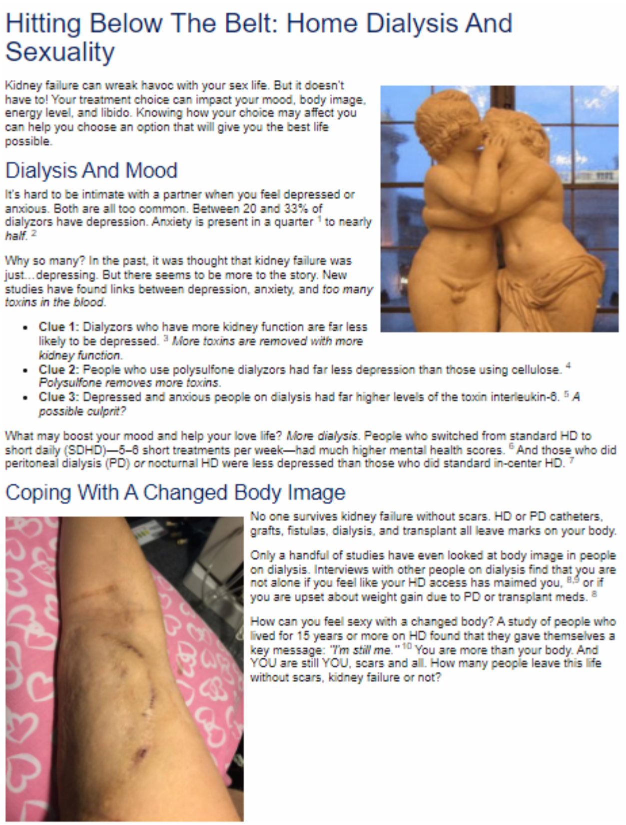
End-Stage Renal Disease
Network Program



Addressing Body Image with Peritoneal Dialysis

Michelle Prager, MSW, LSW
Quality Improvement Lead

Mitigating the Barriers



Hitting Below The Belt: Home Dialysis And Sexuality

Kidney failure can wreak havoc with your sex life. But it doesn't have to! Your treatment choice can impact your mood, body image, energy level, and libido. Knowing how your choice may affect you can help you choose an option that will give you the best life possible.

Dialysis And Mood

It's hard to be intimate with a partner when you feel depressed or anxious. Both are all too common. Between 20 and 33% of dialyzors have depression. Anxiety is present in a quarter [1] to nearly *half*. [2]

Why so many? In the past, it was thought that kidney failure was just…depressing. But there seems to be more to the story. New studies have found links between depression, anxiety, and *too many toxins in the blood*.

- **Clue 1:** Dialyzors who have more kidney function are far less likely to be depressed. [3] *More toxins are removed with more kidney function.*
- **Clue 2:** People who use polysulfone dialyzors had far less depression than those using cellulose. [4] *Polysulfone removes more toxins.*
- **Clue 3:** Depressed and anxious people on dialysis had far higher levels of the toxin interleukin-6. [5] *A possible culprit?*

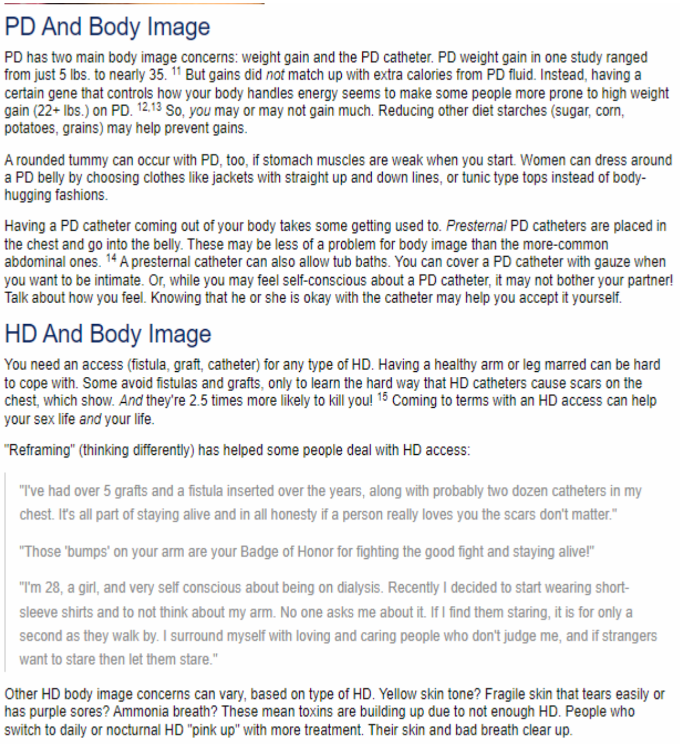
What may boost your mood and help your love life? *More dialysis*. People who switched from standard HD to short daily (SDHD)—5–6 short treatments per week—had much higher mental health scores. [6] And those who did peritoneal dialysis (PD) *or* nocturnal HD were less depressed than those who did standard in-center HD. [7]

Coping With A Changed Body Image

No one survives kidney failure without scars. HD or PD catheters, grafts, fistulas, dialysis, and transplant all leave marks on your body.

Only a handful of studies have even looked at body image in people on dialysis. Interviews with other people on dialysis find that you are not alone if you feel like your HD access has maimed you, [8,9] or if you are upset about weight gain due to PD or transplant meds. [8]

How can you feel sexy with a changed body? A study of people who lived for 15 years or more on HD found that they gave themselves a key message: *"I'm still me."* [10] You are more than your body. And YOU are still YOU, scars and all. How many people leave this life without scars, kidney failure or not?



PD And Body Image

PD has two main body image concerns: weight gain and the PD catheter. PD weight gain in one study ranged from just 5 lbs. to nearly 35. [11] But gains did *not* match up with extra calories from PD fluid. Instead, having a certain gene that controls how your body handles energy seems to make some people more prone to high weight gain (22+ lbs.) on PD. [12,13] So, *you* may or may not gain much. Reducing other diet starches (sugar, corn, potatoes, grains) may help prevent gains.

A rounded tummy can occur with PD, too, if stomach muscles are weak when you start. Women can dress around a PD belly by choosing clothes like jackets with straight up and down lines, or tunic type tops instead of body-hugging fashions.

Having a PD catheter coming out of your body takes some getting used to. *Presternal* PD catheters are placed in the chest and go into the belly. These may be less of a problem for body image than the more-common abdominal ones. [14] A presternal catheter can also allow tub baths. You can cover a PD catheter with gauze when you want to be intimate. Or, while you may feel self-conscious about a PD catheter, it may not bother your partner! Talk about how you feel. Knowing that he or she is okay with the catheter may help you accept it yourself.

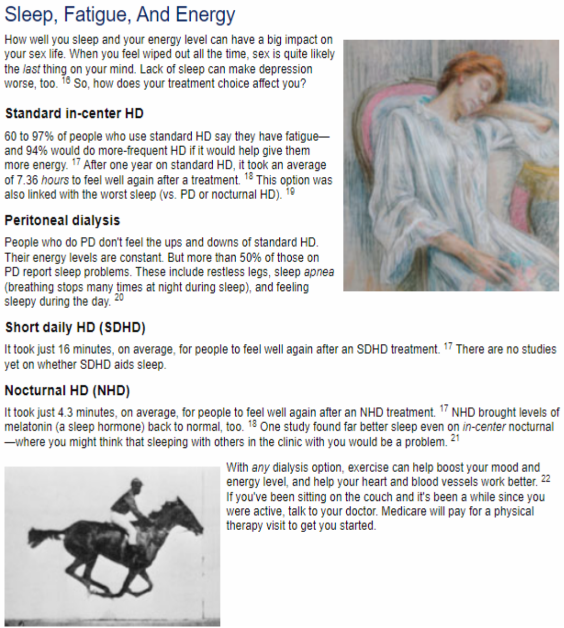
HD And Body Image

You need an access (fistula, graft, catheter) for any type of HD. Having a healthy arm or leg marred can be hard to cope with. Some avoid fistulas and grafts, only to learn the hard way that HD catheters cause scars on the chest, which show. *And* they're 2.5 times more likely to kill you! [15] Coming to terms with an HD access can help your sex life *and* your life.

"Reframing" (thinking differently) has helped some people deal with HD access:

> "I've had over 5 grafts and a fistula inserted over the years, along with probably two dozen catheters in my chest. It's all part of staying alive and in all honesty if a person really loves you the scars don't matter."
>
> "Those 'bumps' on your arm are your Badge of Honor for fighting the good fight and staying alive!"
>
> "I'm 28, a girl, and very self conscious about being on dialysis. Recently I decided to start wearing short-sleeve shirts and to not think about my arm. No one asks me about it. If I find them staring, it is for only a second as they walk by. I surround myself with loving and caring people who don't judge me, and if strangers want to stare then let them stare."

Other HD body image concerns can vary, based on type of HD. Yellow skin tone? Fragile skin that tears easily or has purple sores? Ammonia breath? These mean toxins are building up due to not enough HD. People who switch to daily or nocturnal HD "pink up" with more treatment. Their skin and bad breath clear up.



Sleep, Fatigue, And Energy

How well you sleep and your energy level can have a big impact on your sex life. When you feel wiped out all the time, sex is quite likely the *last* thing on your mind. Lack of sleep can make depression worse, too. [16] So, how does your treatment choice affect you?

Standard in-center HD

60 to 97% of people who use standard HD say they have fatigue—and 94% would do more-frequent HD if it would help give them more energy. [17] After one year on standard HD, it took an average of 7.36 *hours* to feel well again after a treatment. [18] This option was also linked with the worst sleep (vs. PD or nocturnal HD). [19]

Peritoneal dialysis

People who do PD don't feel the ups and downs of standard HD. Their energy levels are constant. But more than 50% of those on PD report sleep problems. These include restless legs, sleep *apnea* (breathing stops many times at night during sleep), and feeling sleepy during the day. [20]

Short daily HD (SDHD)

It took just 16 minutes, on average, for people to feel well again after an SDHD treatment. [17] There are no studies yet on whether SDHD aids sleep.

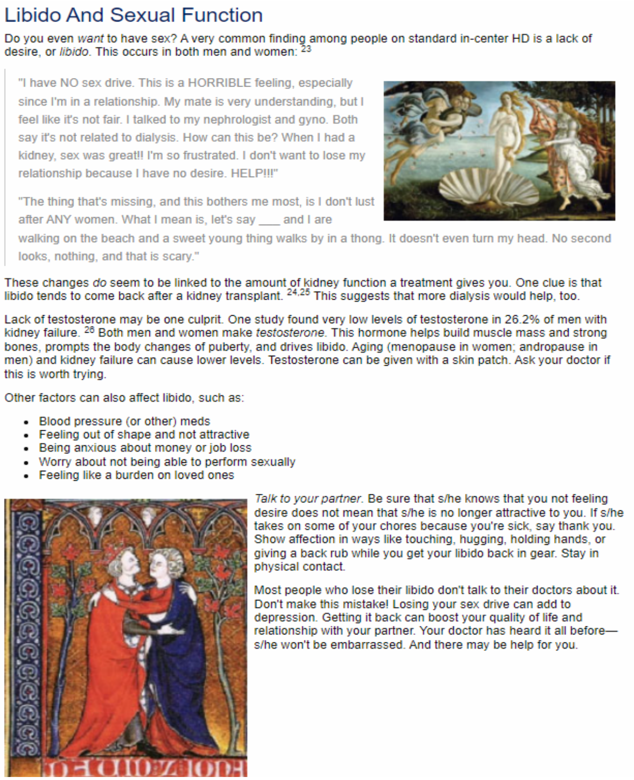
Nocturnal HD (NHD)

It took just 4.3 minutes, on average, for people to feel well again after an NHD treatment. [17] NHD brought levels of melatonin (a sleep hormone) back to normal, too. [18] One study found far better sleep even on *in-center* nocturnal—where you might think that sleeping with others in the clinic with you would be a problem. [21]

With *any* dialysis option, exercise can help boost your mood and energy level, and help your heart and blood vessels work better. [22] If you've been sitting on the couch and it's been a while since you were active, talk to your doctor. Medicare will pay for a physical therapy visit to get you started.

Image Source: Home Dialysis Central [Hitting Below the Belt: Home Dialysis and Sexuality - Home Dialysis Central]

Mitigating the Barriers



Libido And Sexual Function

Do you even *want* to have sex? A very common finding among people on standard in-center HD is a lack of desire, or *libido*. This occurs in both men and women: [23]

> "I have NO sex drive. This is a HORRIBLE feeling, especially since I'm in a relationship. My mate is very understanding, but I feel like it's not fair. I talked to my nephrologist and gyno. Both say it's not related to dialysis. How can this be? When I had a kidney, sex was great!! I'm so frustrated. I don't want to lose my relationship because I have no desire. HELP!!!"
>
> "The thing that's missing, and this bothers me most, is I don't lust after ANY women. What I mean is, let's say ___ and I are walking on the beach and a sweet young thing walks by in a thong. It doesn't even turn my head. No second looks, nothing, and that is scary."

These changes *do* seem to be linked to the amount of kidney function a treatment gives you. One clue is that libido tends to come back after a kidney transplant. [24,25] This suggests that more dialysis would help, too.

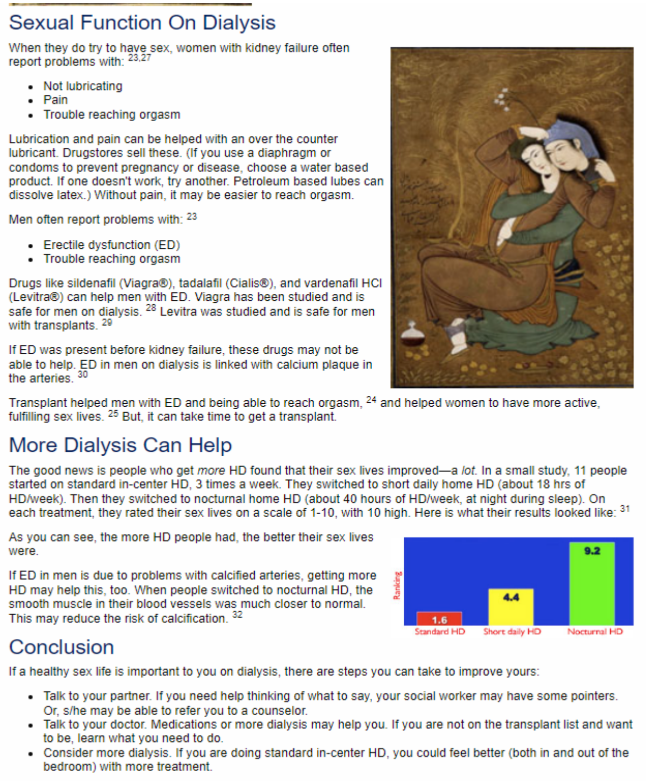
Lack of testosterone may be one culprit. One study found very low levels of testosterone in 26.2% of men with kidney failure. [26] Both men and women make *testosterone*. This hormone helps build muscle mass and strong bones, prompts the body changes of puberty, and drives libido. Aging (menopause in women; andropause in men) and kidney failure can cause lower levels. Testosterone can be given with a skin patch. Ask your doctor if this is worth trying.

Other factors can also affect libido, such as:

- Blood pressure (or other) meds
- Feeling out of shape and not attractive
- Being anxious about money or job loss
- Worry about not being able to perform sexually
- Feeling like a burden on loved ones

Talk to your partner. Be sure that s/he knows that you not feeling desire does not mean that s/he is no longer attractive to you. If s/he takes on some of your chores because you're sick, say thank you. Show affection in ways like touching, hugging, holding hands, or giving a back rub while you get your libido back in gear. Stay in physical contact.

Most people who lose their libido don't talk to their doctors about it. Don't make this mistake! Losing your sex drive can add to depression. Getting it back can boost your quality of life and relationship with your partner. Your doctor has heard it all before—s/he won't be embarrassed. And there may be help for you.



Sexual Function On Dialysis

When they do try to have sex, women with kidney failure often report problems with: [23,27]

- Not lubricating
- Pain
- Trouble reaching orgasm

Lubrication and pain can be helped with an over the counter lubricant. Drugstores sell these. (If you use a diaphragm or condoms to prevent pregnancy or disease, choose a water based product. If one doesn't work, try another. Petroleum based lubes can dissolve latex.) Without pain, it may be easier to reach orgasm.

Men often report problems with: [23]

- Erectile dysfunction (ED)
- Trouble reaching orgasm

Drugs like sildenafil (Viagra®), tadalafil (Cialis®), and vardenafil HCl (Levitra®) can help men with ED. Viagra has been studied and is safe for men on dialysis. [28] Levitra was studied and is safe for men with transplants. [29]

If ED was present before kidney failure, these drugs may not be able to help. ED in men on dialysis is linked with calcium plaque in the arteries. [30]

Transplant helped men with ED and being able to reach orgasm, [24] and helped women to have more active, fulfilling sex lives. [25] But, it can take time to get a transplant.

More Dialysis Can Help

The good news is people who get *more* HD found that their sex lives improved—a *lot*. In a small study, 11 people started on standard in-center HD, 3 times a week. They switched to short daily home HD (about 18 hrs of HD/week). Then they switched to nocturnal home HD (about 40 hours of HD/week, at night during sleep). On each treatment, they rated their sex lives on a scale of 1-10, with 10 high. Here is what their results looked like: [31]

As you can see, the more HD people had, the better their sex lives were.

If ED in men is due to problems with calcified arteries, getting more HD may help this, too. When people switched to nocturnal HD, the smooth muscle in their blood vessels was much closer to normal. This may reduce the risk of calcification. [32]

Conclusion

If a healthy sex life is important to you on dialysis, there are steps you can take to improve yours:

- Talk to your partner. If you need help thinking of what to say, your social worker may have some pointers. Or, s/he may be able to refer you to a counselor.
- Talk to your doctor. Medications or more dialysis may help you. If you are not on the transplant list and want to be, learn what you need to do.
- Consider more dialysis. If you are doing standard in-center HD, you could feel better (both in and out of the bedroom) with more treatment.

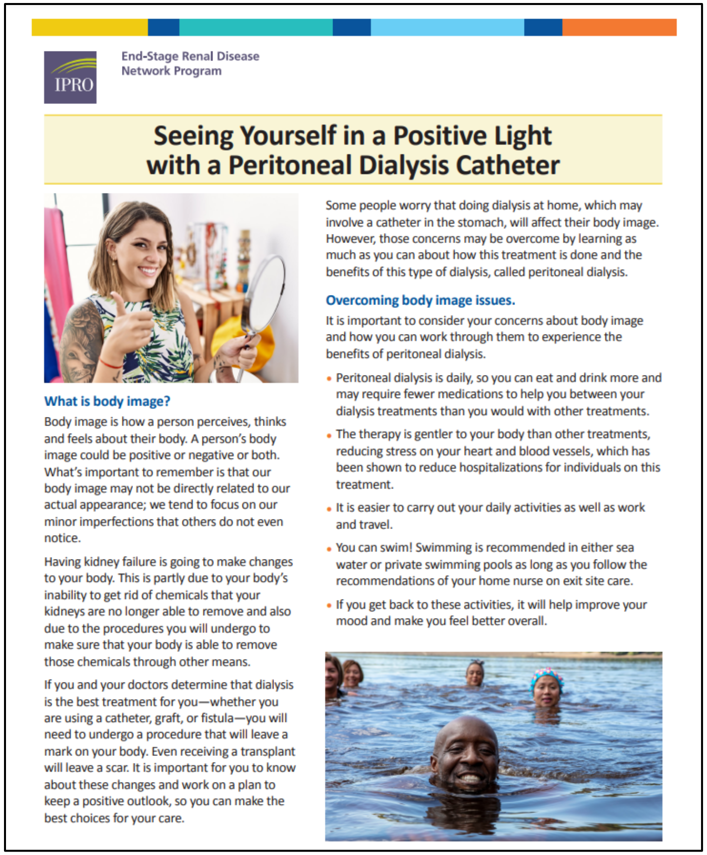
Image Source: Home Dialysis Central Hitting Below the Belt: Home Dialysis and Sexuality - Home Dialysis Central

Results

Hitting Below the Belt: Home Dialysis and Sexuality

- 84% noted that body image is a barrier in promoting PD
- 125 facilities noted coping with a changed body image
- 64 facilities noted PD and body image

Body Image Resource



End-Stage Renal Disease
Network Program

Seeing Yourself in a Positive Light with a Peritoneal Dialysis Catheter

What is body image?

Body image is how a person perceives, thinks and feels about their body. A person's body image could be positive or negative or both. What's important to remember is that our body image may not be directly related to our actual appearance; we tend to focus on our minor imperfections that others do not even notice.

Having kidney failure is going to make changes to your body. This is partly due to your body's inability to get rid of chemicals that your kidneys are no longer able to remove and also due to the procedures you will undergo to make sure that your body is able to remove those chemicals through other means.

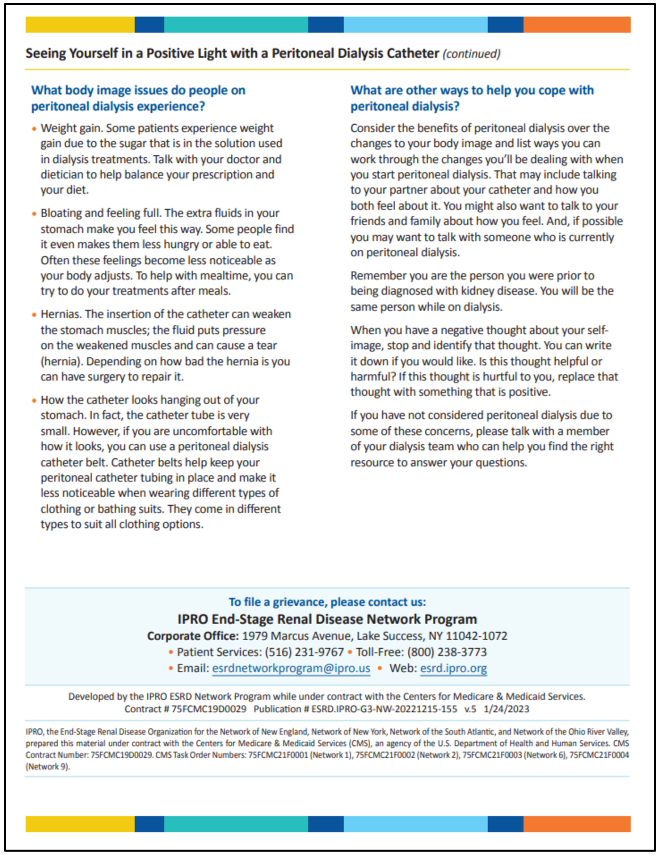
If you and your doctors determine that dialysis is the best treatment for you—whether you are using a catheter, graft, or fistula—you will need to undergo a procedure that will leave a mark on your body. Even receiving a transplant will leave a scar. It is important for you to know about these changes and work on a plan to keep a positive outlook, so you can make the best choices for your care.

Some people worry that doing dialysis at home, which may involve a catheter in the stomach, will affect their body image. However, those concerns may be overcome by learning as much as you can about how this treatment is done and the benefits of this type of dialysis, called peritoneal dialysis.

Overcoming body image issues.

It is important to consider your concerns about body image and how you can work through them to experience the benefits of peritoneal dialysis.

- Peritoneal dialysis is daily, so you can eat and drink more and may require fewer medications to help you between your dialysis treatments than you would with other treatments.
- The therapy is gentler to your body than other treatments, reducing stress on your heart and blood vessels, which has been shown to reduce hospitalizations for individuals on this treatment.
- It is easier to carry out your daily activities as well as work and travel.
- You can swim! Swimming is recommended in either sea water or private swimming pools as long as you follow the recommendations of your home nurse on exit site care.
- If you get back to these activities, it will help improve your mood and make you feel better overall.



Seeing Yourself in a Positive Light with a Peritoneal Dialysis Catheter *(continued)*

What body image issues do people on peritoneal dialysis experience?

- Weight gain. Some patients experience weight gain due to the sugar that is in the solution used in dialysis treatments. Talk with your doctor and dietician to help balance your prescription and your diet.
- Bloating and feeling full. The extra fluids in your stomach make you feel this way. Some people find it even makes them less hungry or able to eat. Often these feelings become less noticeable as your body adjusts. To help with mealtime, you can try to do your treatments after meals.
- Hernias. The insertion of the catheter can weaken the stomach muscles; the fluid puts pressure on the weakened muscles and can cause a tear (hernia). Depending on how bad the hernia is you can have surgery to repair it.
- How the catheter looks hanging out of your stomach. In fact, the catheter tube is very small. However, if you are uncomfortable with how it looks, you can use a peritoneal dialysis catheter belt. Catheter belts help keep your peritoneal catheter tubing in place and make it less noticeable when wearing different types of clothing or bathing suits. They come in different types to suit all clothing options.

What are other ways to help you cope with peritoneal dialysis?

Consider the benefits of peritoneal dialysis over the changes to your body image and list ways you can work through the changes you'll be dealing with when you start peritoneal dialysis. That may include talking to your partner about your catheter and how you both feel about it. You might also want to talk to your friends and family about how you feel. And, if possible you may want to talk with someone who is currently on peritoneal dialysis.

Remember you are the person you were prior to being diagnosed with kidney disease. You will be the same person while on dialysis.

When you have a negative thought about your self-image, stop and identify that thought. You can write it down if you would like. Is this thought helpful or harmful? If this thought is hurtful to you, replace that thought with something that is positive.

If you have not considered peritoneal dialysis due to some of these concerns, please talk with a member of your dialysis team who can help you find the right resource to answer your questions.

To file a grievance, please contact us:
IPRO End-Stage Renal Disease Network Program
Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11042-1072
• Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773
• Email: esrdnetworkprogram@ipro.us • Web: esrd.ipro.org

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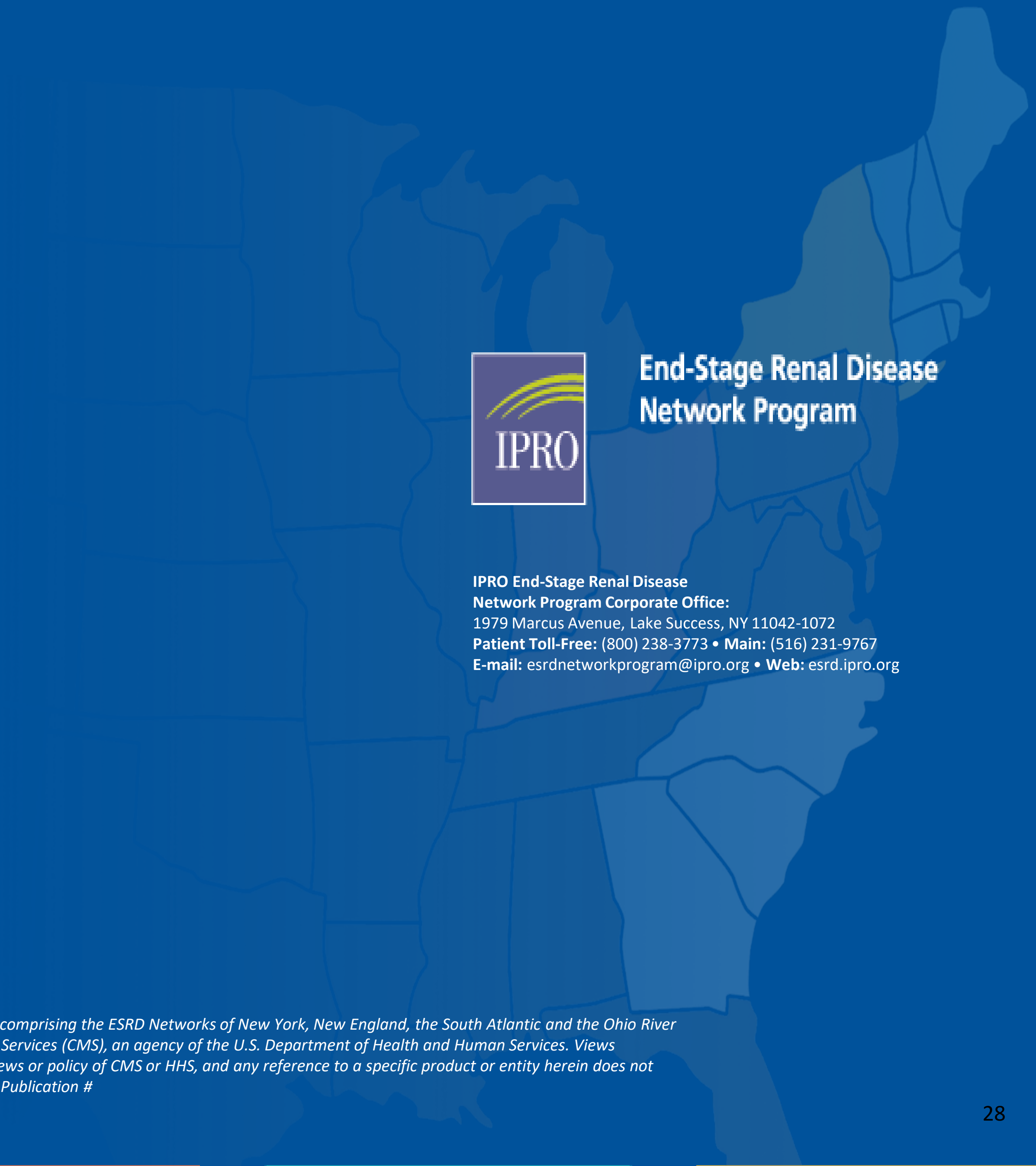
Image Source: IPRO



Thank you!

End-Stage Renal Disease
Network Program

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PERITONEAL DIALYSIS

BARRIERS

PRESENTERS

SHANNON PLAINE, RN

Shannon Plaine has been in health care for >18 years. Started as a STNA, then an RN in a stepdown unit and currently she has been in dialysis for 12 years. She started as a floor nurse, became an in-center facility administrator and is currently a home therapies facility administrator.

HEATHER OWENS, RN

Heather Owens has been in healthcare for >26 years. She started as an STNA, moving onto a dialysis PCT while in nursing school. She then moved into a dialysis RN position for in-center hemodialysis and hospital acutes for 10 years. She became a facility administrator of in-center hemodialysis program in 2008 where she still remains.

PRESENTERS

Image Source: Heather Owens

DANA PHLEGAR, KCO EDUCATOR

Dana Phlegar has been in the dialysis field since 1988. She has worked in all aspects of dialysis. She continues to remain a certified direct patient care technician. She has worked as a biomed technician, and biomedical technician manager maintaining all dialysis equipment. She is currently a kidney care options educator for US Renal Care facilities in Northwest Ohio and with the CKD patients of Nephrology Consultants of NW Ohio.

CKD = chronic kidney disease

OUR OPTIONS EDUCATION

- In our area, our nephrologist use a KCO (kidney care options) educator.
- The Nephrology Office sends out the KCO educator (stage lV-V) to speak with patients about treatment options including;
  - In-center Hemodialysis
  - Peritoneal Dialysis (CCPD, CAPD)
  - Home Hemo
  - Transplant
  - No treatment option

New patient starts in the center that have not had treatment options are also referred to the KCO educator to make informed treatment decisions.

CCPD = Continuous cycling peritoneal dialysis
CAPD = Continuous ambulatory peritoneal dialysis

EDUCATION MATERIAL

- Life-size example with accessories is presented to the patient.
- All patients are offered to visit our centers for a tour, meet and talk with staff and a patient representative.
- Several meetings are often held with the patient and other family members.
- Patients (office and clinic) offered a round-table call bimonthly to discuss any barriers or dialysis related questions.

Image Source: Heather Owens

PATIENT CHOICE

- What fits best with their life?
- Employment, and how dialysis will fit in.
- Living situation/House, hotel, apartment, homeless
- Space for supplies
- Pets
- Mental and physical barriers
- Back-up caregiver support

- These are common discussion topics during education. Focus on what is best for the patient and their family. We focus on the mental and physical barriers.

BARRIERS

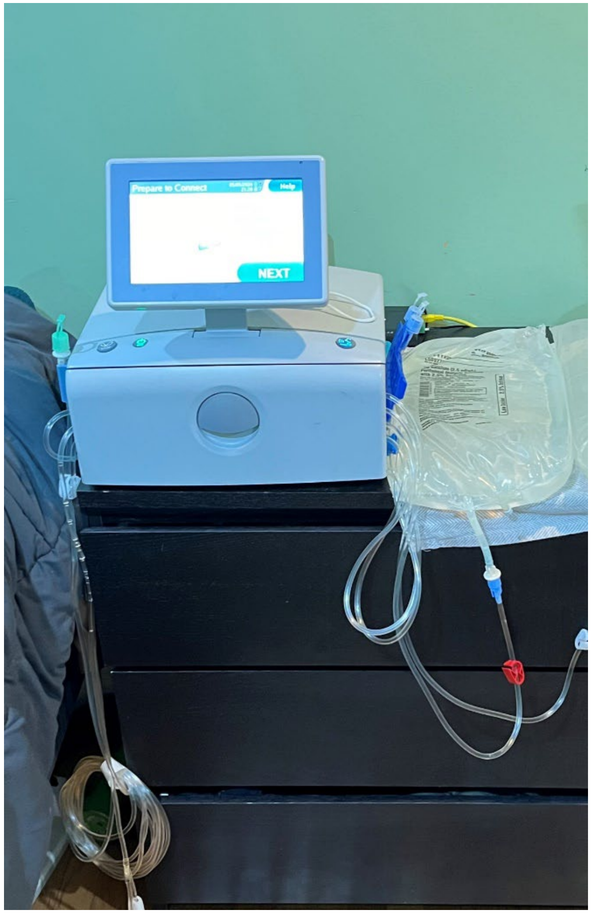


Image Source: Heather Owens

1. Time
    - Prescription/Cycler
2. Ability to do it
    - Physical/Mental
3. Space
    - Supplies
4. Leisure Activities
    - Swimming/Lifting
5. Body Image

BODY IMAGE BARRIERS

- Weight Gain
- Fluid in the abdomen/bloated
- Tube hanging out
- Showering/Infection
- How the access is going to look- afraid people will see it
- They don't want people to know they are on dialysis (embarrassed)
- They don't feel attractive
- Intimacy
- Quality of life can I still do what I want with traveling and eating

SUGGESTIONS

- Talk with someone who has already gone through this
- Use a belt/tape/lanyard for PD tubing to keep tube in place
- Teach them they can shower, travel
- Wear tank top during intimate moments
- People who are not close to you do not even have to know you are on dialysis
- You can travel! Just takes a bit of planning.
- Coping with changes, consider referring patients to the dialysis on-line support community

Image Source: Heather Owens

PROBLEMS ARISE

LISTEN TO YOUR PATIENT

- Scheduling (outings/activities)
- Share with your nurse (fill volume/plans)
- What to do with your PD catheter (belt/lanyard)
- Infection (act/report quickly)
- Prevention of problem
    - Sleep disturbance
    - Time consuming/treatments
    - Appetite fullness
    - Medication changes
    - Family and friends don't really understand what is going on

Home Dialysis is the first choice for preservation of kidney function. However, we must listen to the patient and help them figure what kidney replacement option fits them best. Remember, We are all here for the patients!

PRESENTER

Image Source: Bob McDonagh

- My name is Bob McDonagh, I'm 67 years old, married with 5 children, 10 grandchildren and one great grandchild. I have lived in Toledo, Ohio all of my life. In my professional life, I worked as a machinist and as a plastic injection mold maker. I am passionate about my faith as a Catholic Christian and family time with my wife, our kids and grandkids. I have several hobbies which I enjoy. They are camping with family and friends and working in my wood shop.
- I have had kidney problems since a young child, resulting in the need for a kidney transplant in October of 1987 at the age of 30. My transplant lasted 14 years and allowed me to live a relatively normal life, with the need for blood work and for seeing doctors reduced as well as greatly increased energy levels and a normal diet. My transplant began to fail in 2001 so that by February of 2002, I needed to start peritoneal dialysis. I did well on this for 4 years until a health challenge arose and the need to turn to hemo-dialysis in November of 2006. I remained on hemo-dialysis until February of 2023 when I received my second lifesaving transplant. Now, over a year and a half since the transplant, I have blood work once per month as the transplant team monitors my kidney function and I'm seeing my nephrologist every 3 months for a checkup. I'm eating a normal diet again and working on recovering from my 21 years on dialysis.

FROM A PATIENT PERSPECTIVE

- How to make this your normal and live your life?
- Personal Hurdles
  - Clothing/fitting
  - Body image, catheter, T-shirt belts, tape
  - Skin sore from tape/catheter issue
  - Weight gains/shifts
  - Changes in dialysis modality/diet
  - Adjustment with partner/life
  - Diet challenges
  - Travel/leisure activities

Let Us Hear From You

Pt2

Questions and Answers

NPFE-LAN Patient Summit

Going for the Gold: Overcoming Obstacles

Break time.

The program will resume at 2:30 p.m. ET.

NPFE-LAN=National Patient and Family Engagement (NPFE) Learning and Action Network (LAN)

NPFE-LAN Patient Summit

Going for the Gold:
Overcoming Obstacles

Tennessee Kidney Foundation

Heather Corum Powell
Jacfranz Guiteau, MD
Jonathan Trees

NPFE-LAN=National Patient and Family Engagement (NPFE) Learning and Action Network (LAN)

ESRD NCC Patient Summit

Importance of Living Donation

Ascension

Listening to you, caring for you.®

Introduction

Learning Objectives

You should be able to:

- Describe the advantages of transplant
- Understand why living donation is the best treatment option

Advantages of Transplant

Treatment options for ESRD

- Do nothing
- Dialysis
  - Hemodialysis
  - Peritoneal dialysis
- Transplant
  - Deceased donor kidney transplant
  - Living donor kidney transplant

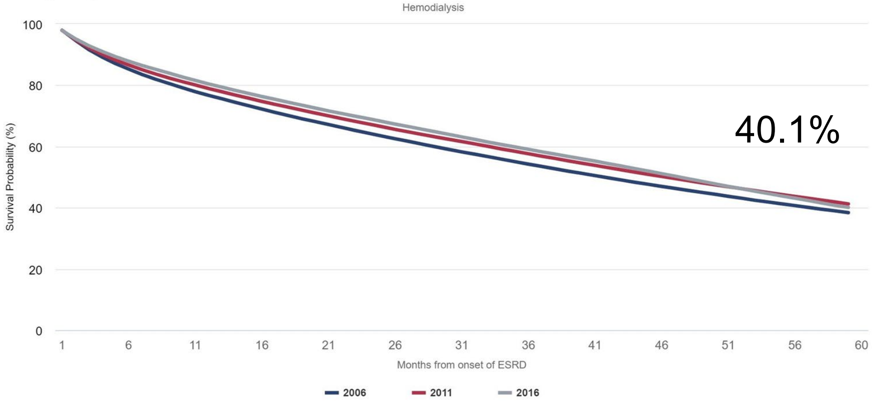
Advantages of Transplant

Dialysis vs. Transplant

- Live longer
- Feel better
- More time for family, work, and other activities
- Less dietary restrictions
- Improved fertility/sexual function
- Improved anemia, hyperparathyroidism
- Ability to travel

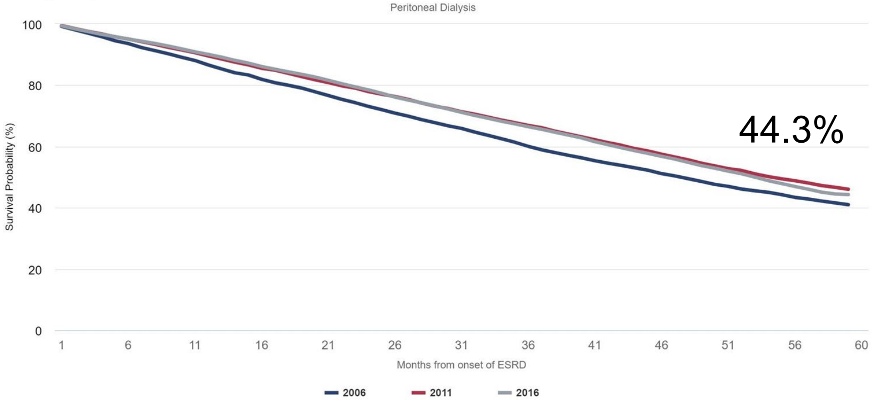
Advantages of Transplant

Figure 6.7 Adjusted survival of incident ESRD patients over the first 5 years after onset of ESRD, by treatment modality and year of ESRD onset, 2006, 20011, and 2016



Data Source: 2022 United States Renal Data System Annual Data Report

Figure 6.7 Adjusted survival of incident ESRD patients over the first 5 years after onset of ESRD, by treatment modality and year of ESRD onset, 2006, 20011, and 2016



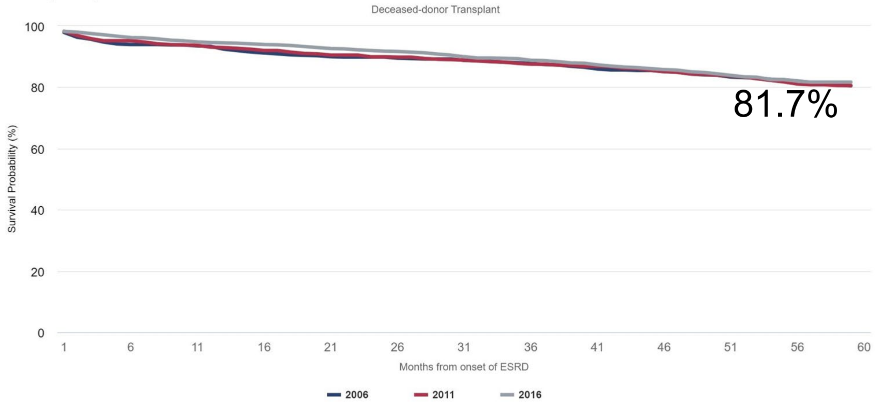
Data Source: 2022 United States Renal Data System Annual Data Report

- ~1 of 5 patients die within a year of starting dialysis
- Over 50% of patients started on dialysis will die within the first 5 years of starting treatment

Image Source: 2022 United States Renal Data System Annual Data Report

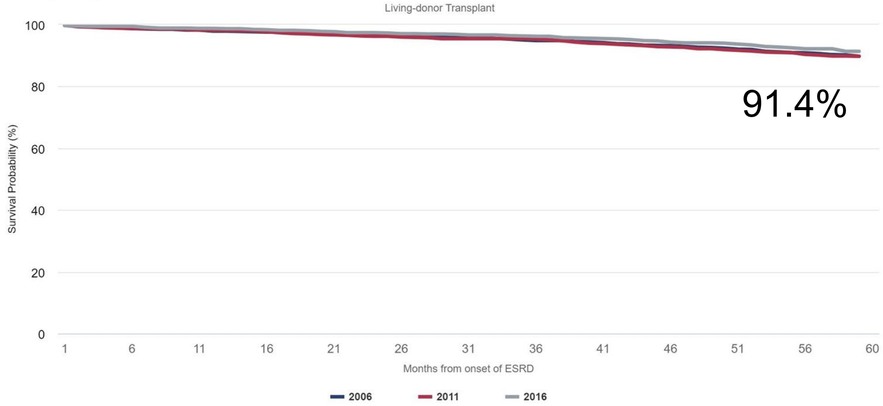
Advantages of Transplant

Figure 6.7 Adjusted survival of incident ESRD patients over the first 5 years after onset of ESRD, by treatment modality and year of ESRD onset, 2006, 20011, and 2016



Data Source: 2022 United States Renal Data System Annual Data Report

Figure 6.7 Adjusted survival of incident ESRD patients over the first 5 years after onset of ESRD, by treatment modality and year of ESRD onset, 2006, 20011, and 2016



Data Source: 2022 United States Renal Data System Annual Data Report

- Over 90% of patients who are transplanted are alive at 1 year after transplant
- Over 80% of patients transplanted are alive at 5 years after transplant

Image Source: 2022 United States Renal Data System Annual Data Report

Dialysis vs. Transplant

- Transplant improves your quality and length of life
- It is considered the gold standard of treatment for ESRD
- It is not without risks, however:
    - Risks of major surgery
    - Risks of lifelong immunosuppression
    - Lifelong follow up

ESRD = end stage renal disease

Why strive for a live donor?

Why a Living Donor Kidney Transplant

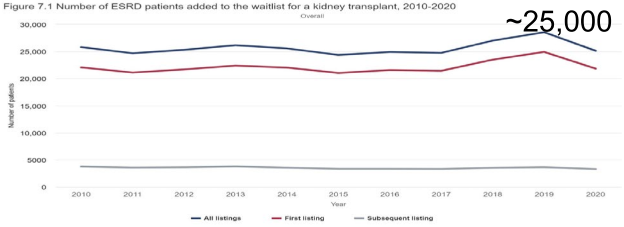


Figure 7.1 Number of ESRD patients added to the waitlist for a kidney transplant, 2010-2020

Data Source: 2022 United States Renal Data System Annual Data Report

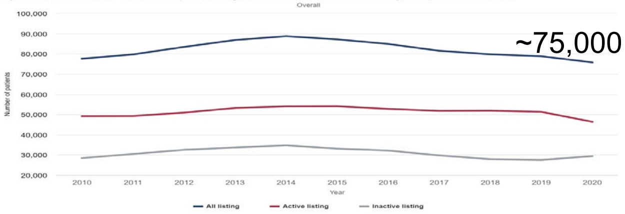


Figure 7.2 Total number of all ESRD patients registered on the waitlist for a kidney transplant, 2010-2020

Data Source: 2022 United States Renal Data System Annual Data Report

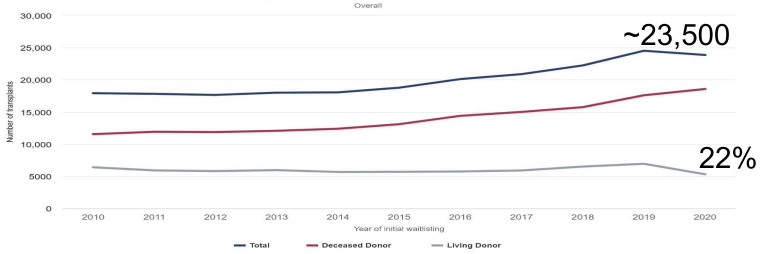


Figure 7.10b Number of kidney transplants in patients undergoing dialysis, 2010-2020

Data Source: 2022 United States Renal Data System Annual Data Report

- There are ~75,000 people on the kidney transplant waiting list
- We do ~23,500 transplants per year, while adding ~25,000 new patients to the list
- Longer waiting list = longer waiting times with the current times being 3 - 7 years

Image Source: 2022 United States Renal Data System Annual Data Report

Why a Living Donor Kidney Transplant

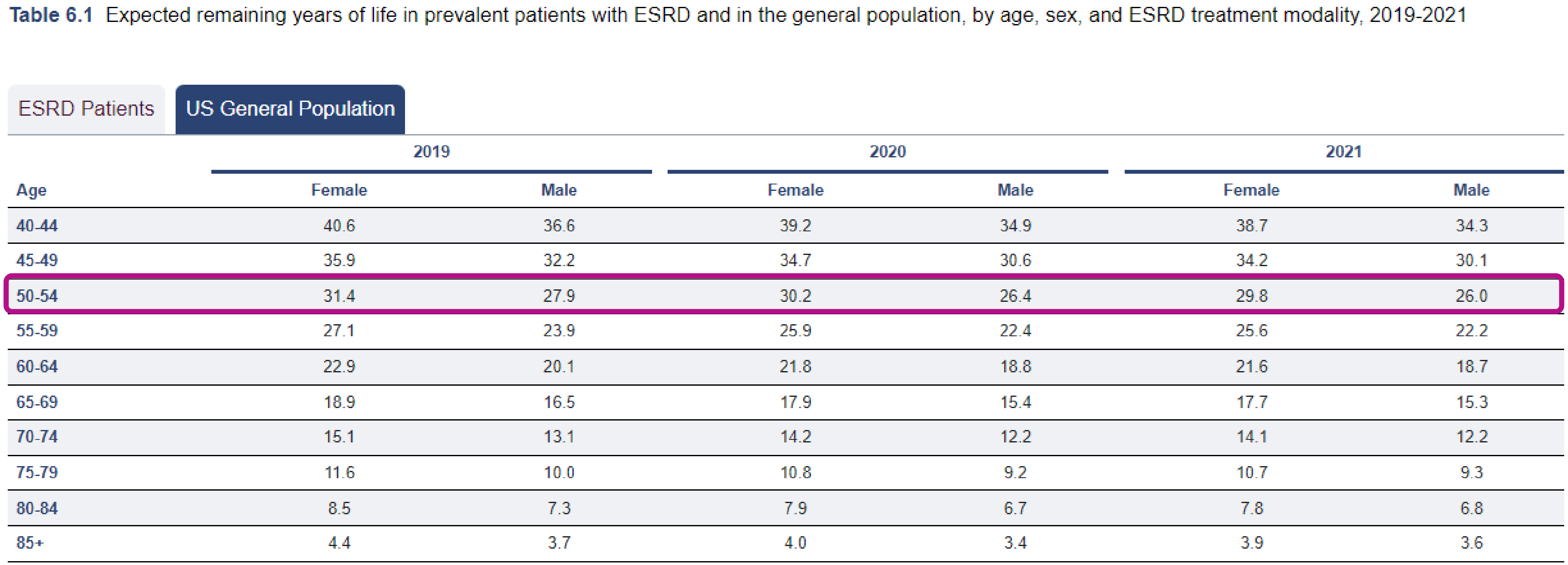


Table 6.1 Expected remaining years of life in prevalent patients with ESRD and in the general population, by age, sex, and ESRD treatment modality, 2019-2021

	2019		2020		2021	
Age	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**
40-44	40.6	36.6	39.2	34.9	38.7	34.3
45-49	35.9	32.2	34.7	30.6	34.2	30.1
50-54	31.4	27.9	30.2	26.4	29.8	26.0
55-59	27.1	23.9	25.9	22.4	25.6	22.2
60-64	22.9	20.1	21.8	18.8	21.6	18.7
65-69	18.9	16.5	17.9	15.4	17.7	15.3
70-74	15.1	13.1	14.2	12.2	14.1	12.2
75-79	11.6	10.0	10.8	9.2	10.7	9.3
80-84	8.5	7.3	7.9	6.7	7.8	6.8
85+	4.4	3.7	4.0	3.4	3.9	3.6

Image Source: USRDS ESRD database.

Why a Living Donor Kidney Transplant

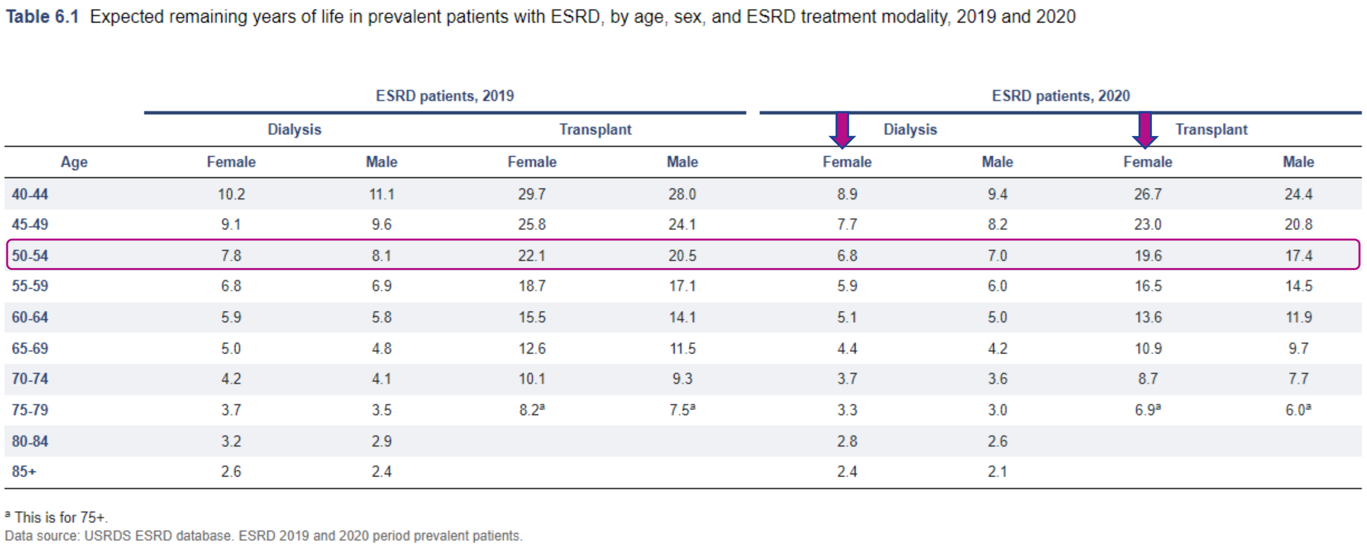


Table 6.1 Expected remaining years of life in prevalent patients with ESRD, by age, sex, and ESRD treatment modality, 2019 and 2020

	ESRD patients, 2019				ESRD patients, 2020			
	Dialysis		Transplant		Dialysis		Transplant	
Age	Female	Male	Female	Male	Female	Male	Female	Male
40-44	10.2	11.1	29.7	28.0	8.9	9.4	26.7	24.4
45-49	9.1	9.6	25.8	24.1	7.7	8.2	23.0	20.8
50-54	7.8	8.1	22.1	20.5	6.8	7.0	19.6	17.4
55-59	6.8	6.9	18.7	17.1	5.9	6.0	16.5	14.5
60-64	5.9	5.8	15.5	14.1	5.1	5.0	13.6	11.9
65-69	5.0	4.8	12.6	11.5	4.4	4.2	10.9	9.7
70-74	4.2	4.1	10.1	9.3	3.7	3.6	8.7	7.7
75-79	3.7	3.5	8.2[a]	7.5[a]	3.3	3.0	6.9[a]	6.0[a]
80-84	3.2	2.9			2.8	2.6		
85+	2.6	2.4			2.4	2.1		

[a] This is for 75+.

Data source: USRDS ESRD database. ESRD 2019 and 2020 period prevalent patients.

- So, if you are 50+ years old, there is a chance you could die before a deceased donor kidney transplant is available

TIME is of the essence!

Image Source: USRDS ESRD database.

Why a Living Donor Kidney Transplant

Unadjusted graft survival in 56,587 recipients of cadaveric transplants	
Length of Dialysis Before Transplant	**Survival Rate**
Preemptive Group	71%
0-6 months dialysis	49%
6-12 months dialysis	43%
12-24 months dialysis	38%
24+ months dialysis	35%

Unadjusted graft survival in 21,836 recipients of living transplants	
Length of Dialysis Before Transplant	**Survival Rate**
Preemptive Group	78%
0-6 months dialysis	62%
6-12 months dialysis	55%
12-24 months dialysis	50%
24+ months dialysis	48%

- Not only does age affect your life expectancy on dialysis, how long you are on dialysis affects how long your kidney will last!

TIME is of the essence!

Data Source: Meier-Kriesche HU, Kaplan B. *Waiting time on dialysis as the strongest modifiable risk factor for renal transplant outcomes: a paired donor kidney analysis.* Transplantation. 2002 Nov 27;74(10):1377-81.

Why a Living Donor Kidney Transplant

What is the fastest way to get transplanted?

- Living donor kidney transplant!

- Live donor kidney benefits:
  - Get transplanted in months rather than years
  - Live donor kidneys last 2x as long
  - Live donor kidneys have immediate function
  - Plan your operation date and time that is convenient for you and your donor
  - Removes a patient from the kidney transplant waiting list shortening wait times

Frequently Asked Questions

Barriers to Living Donation

FAQ

- Who can be my donor?
  - Must be >18 y/o
  - Family
  - Friends
  - Co-workers
  - Church members
  - Previous classmates
  - Members of your social network
  - A complete stranger
    - 1 in 4 people surveyed said they would be willing to donate a kidney

Barriers to Living Donation

FAQ

- Who pays for the donor’s work up and surgery?
  - All aspects of the donor work up, operation, hospital stay, follow up appointments with labs, and any complications related to donation will be covered by your, the recipient’s, insurance
  - Donors can also apply for federally funded assistance that can cover travel expenses, lodging, meals, and lost wages through the National Living Donor Assistance Center, NLDAC, at *livingdonorassistance.org*
  - Donors that donate through the National Kidney Registry will get more protections through Donor Shield

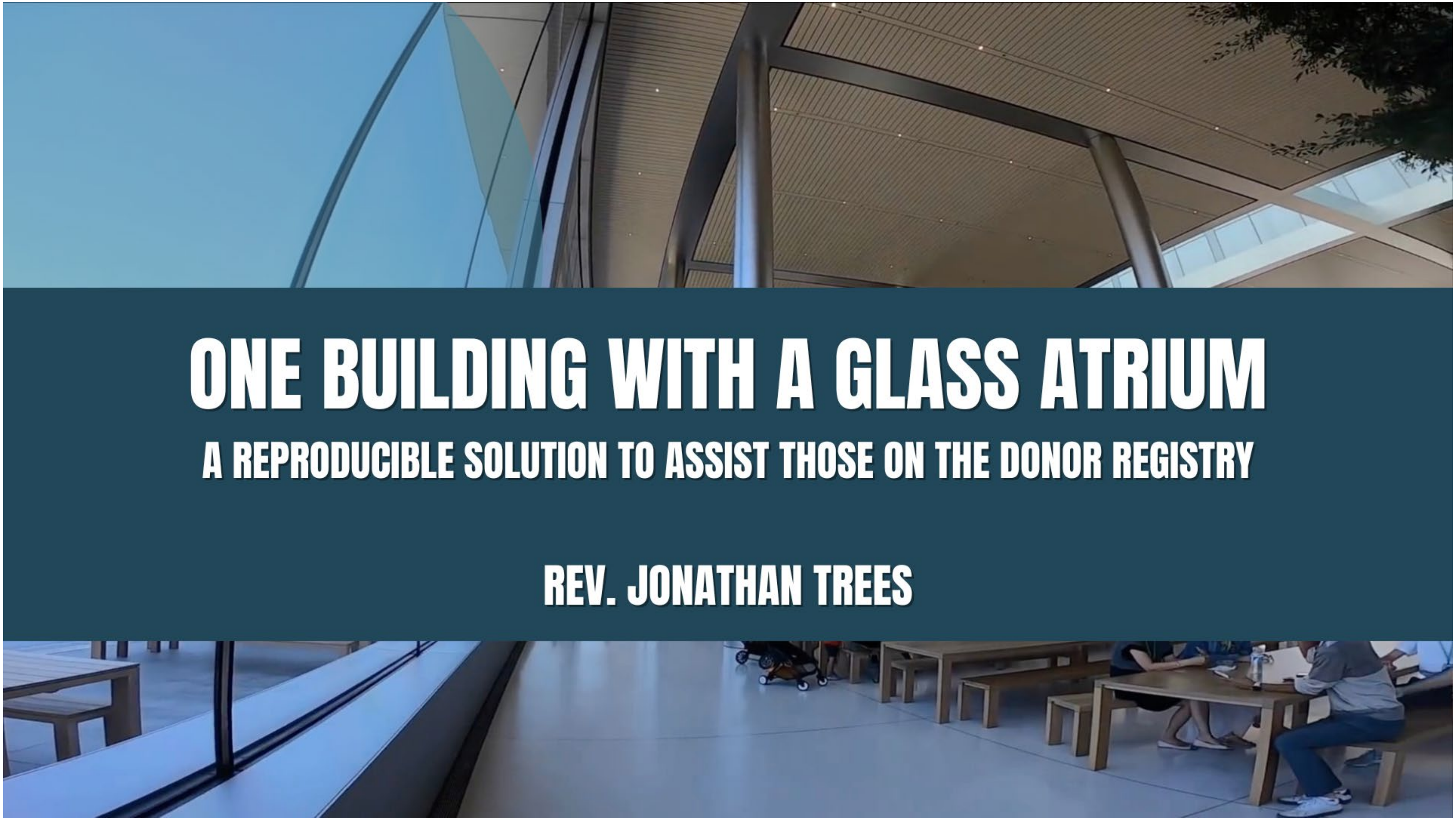
FAQ

- How long is the recovery for a living donor?
  - Since the surgery is done laparoscopically, most donors stay for 1-2 nights
  - Full recovery takes 4-6 weeks (back to sports in 6 weeks)
  - Pain after surgery can generally be controlled with acetaminophen and/or pain medications (pain medications are usually only needed 1-2 weeks after surgery)
  - No dietary restrictions
  - There are risks involved with donation:
    - Surgical complications
    - Longer recovery than anticipated
    - Slight increase in high blood pressure in the long term
    - <1% of live donors develop kidney failure after donation

The End

Questions?

Ascension



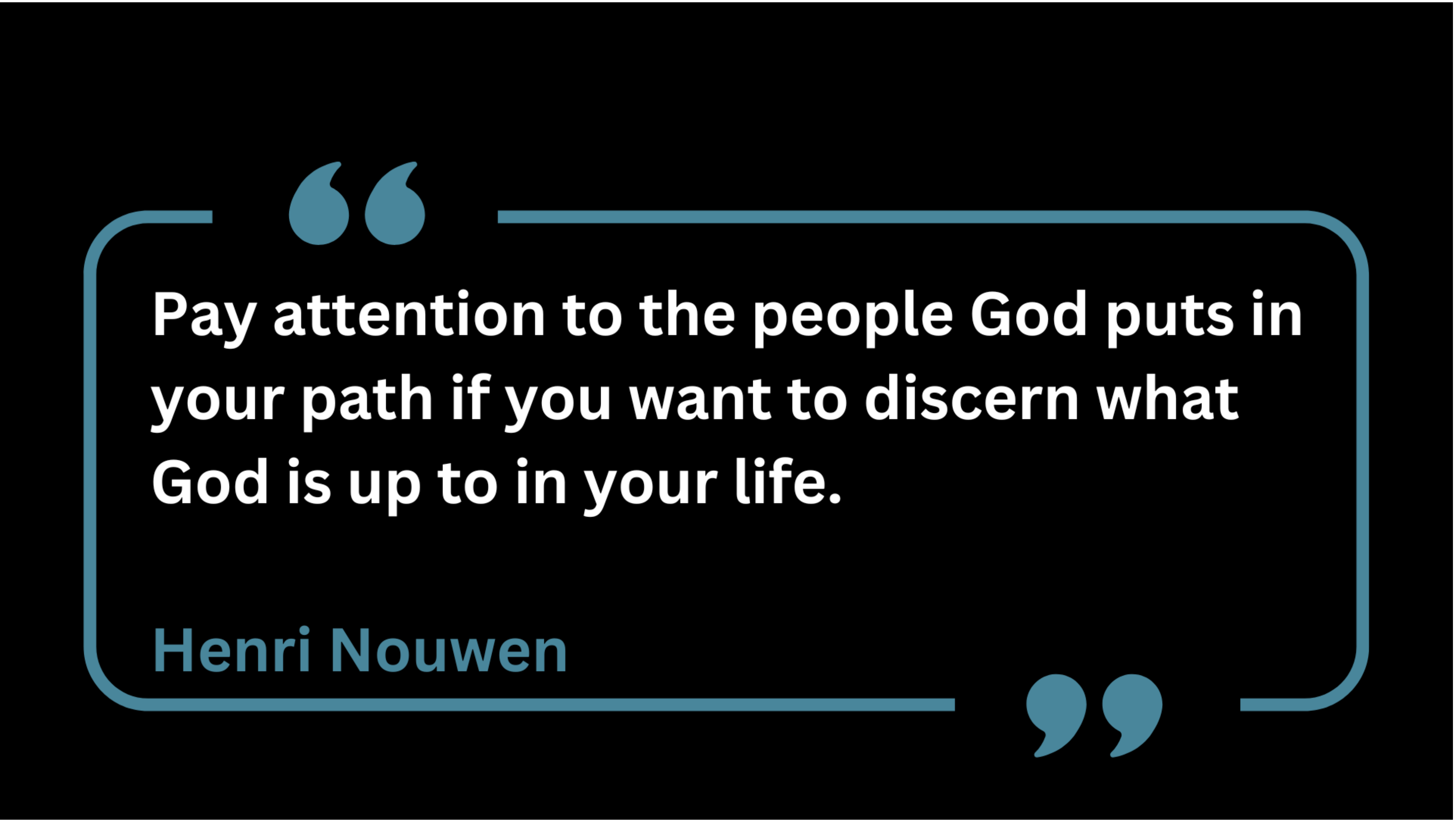
ONE BUILDING WITH A GLASS ATRIUM

A REPRODUCIBLE SOLUTION TO ASSIST THOSE ON THE DONOR REGISTRY

REV. JONATHAN TREES

Image Source: Rev. Jonathan Trees

Image Source: Rev. Jonathan Trees



Pay attention to the people God puts in your path if you want to discern what God is up to in your life.

Henri Nouwen

Image Source: Rev. Jonathan Trees

What would happen if all faith communities hosted a donor campaign to raise compassionate awareness of organ donation?

WHAT HAPPENED IN OUR FAITH-COMMUNITY?

- EXAMINED OUR RESOURCES.
- NOTICED THE GAPS.
- JOYFULLY OFFERED WHAT WE HAD TO BRING HEALING.

TENNESSEE KIDNEY FOUNDATION

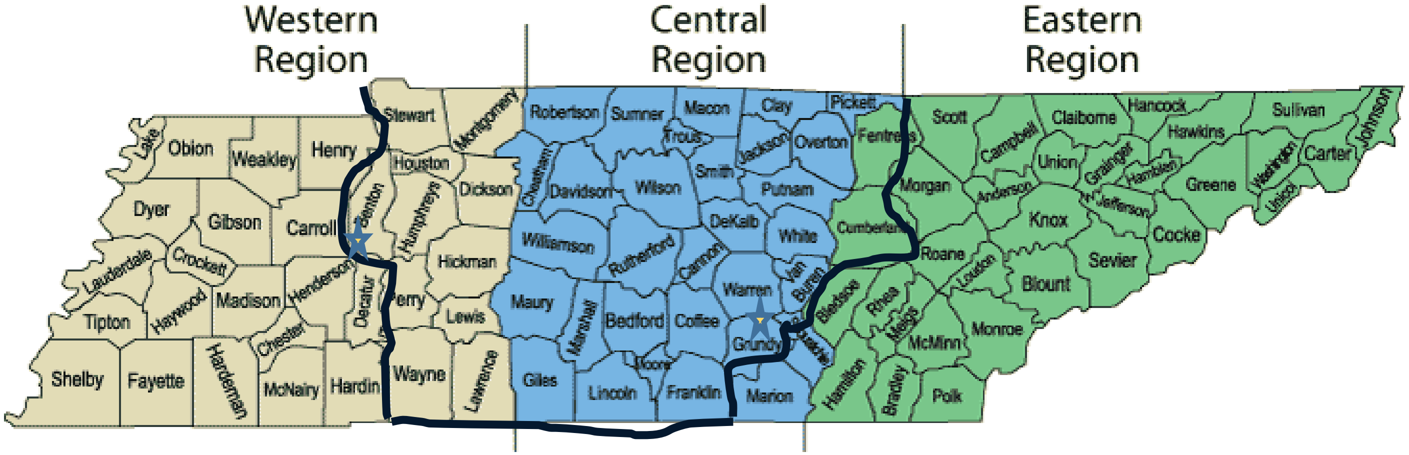
About Tennessee Kidney Foundation

The mission of the Tennessee Kidney Foundation (TKF) is to empower and support those at risk or affected by kidney disease and its vision is a Tennessee where the rate of kidney disease is minimized and everyone who needs care receives care.

TKF was founded in 1972 to meet the needs of the community affected by kidney disease. Facts about TKF:

- Four employees
- 42 county service area
- 40+ referring social workers who work in transplant centers and dialysis clinics throughout the service area
- 60+ dialysis clinics, 3 transplant centers referring direct assistance program participants
- 24-member Board of Directors

TKF programs are transportation assistance for life-saving healthcare; meal program providing renal-friendly meals to the food insecure; emergency financial assistance for housing and utilities; and free preventive kidney health education and screenings.



Tennessee Kidney Foundation
Service Area
42 Counties

Image Source: Tennessee Kidney Foundation

TENNESSEE KIDNEY FOUNDATION

Direct Assistance Programs

Access to Care: Transportation Assistance
TKF provides transportation assistance to and from treatments for dialysis patients, transplant candidates, and transplant recipients.

Emergency Financial Assistance
TKF helps patients with critical needs like housing, utilities, and addressing food security needs.

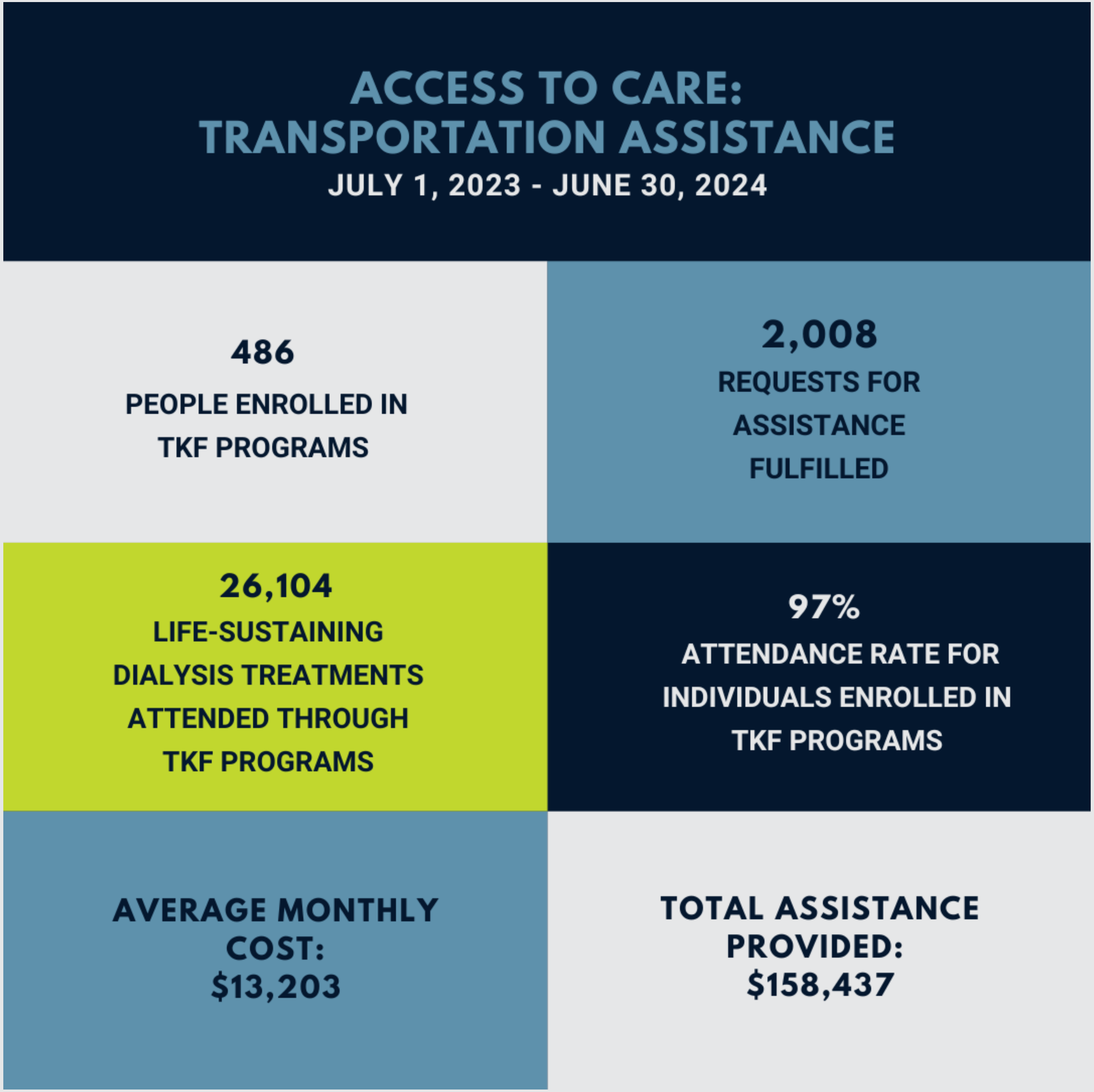
Meal Delivery Service
TKF’s meal delivery program provides clients with 7 freshly-prepared, kidney-friendly meals per week delivered to their homes.

Who are TKF's Direct Assistance Program Clients?

Location	42 Counties in Middle Tennessee
Age	Under 40 - 6% 40-49 - 13% 50-59 - 24% 60+ - 57%
Income	All are 200% or below the Federal Poverty Limit
Ethnicity	62% African American 30% White 8% AAPI/ Hispanic
Risk Factors and Comorbidities	Hypertension Diabetes

Image Source: Tennessee Kidney Foundation

AAPI = Asian American Pacific Islander



ACCESS TO CARE: TRANSPORTATION ASSISTANCE

JULY 1, 2023 - JUNE 30, 2024

486

PEOPLE ENROLLED IN TKF PROGRAMS

2,008

REQUESTS FOR ASSISTANCE FULFILLED

26,104

LIFE-SUSTAINING DIALYSIS TREATMENTS ATTENDED THROUGH TKF PROGRAMS

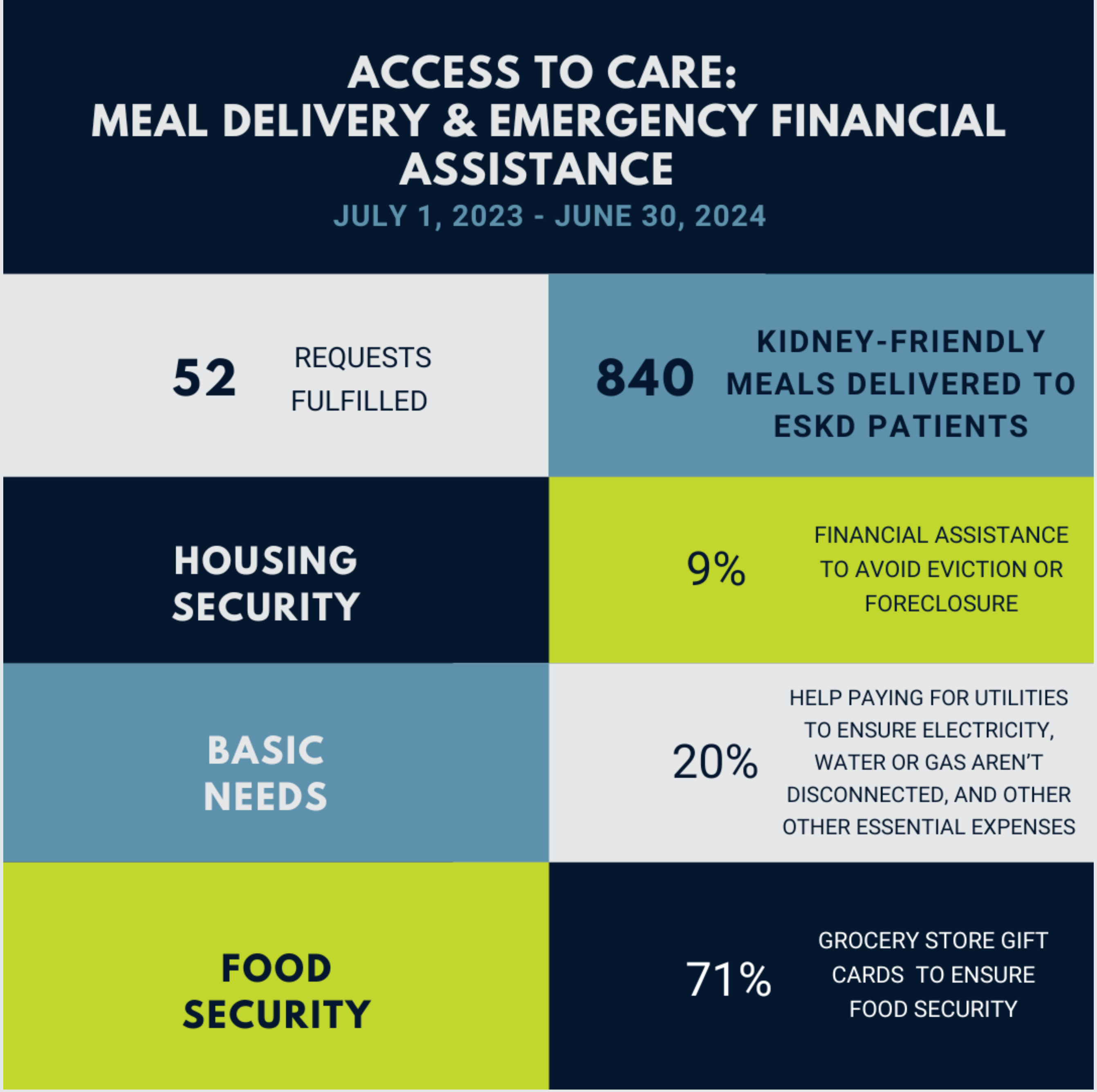
97%

ATTENDANCE RATE FOR INDIVIDUALS ENROLLED IN TKF PROGRAMS

AVERAGE MONTHLY COST:
$13,203

TOTAL ASSISTANCE PROVIDED:
$158,437

Image Source: Tennessee Kidney Foundation



ACCESS TO CARE: MEAL DELIVERY & EMERGENCY FINANCIAL ASSISTANCE

JULY 1, 2023 - JUNE 30, 2024

52 REQUESTS FULFILLED

840 KIDNEY-FRIENDLY MEALS DELIVERED TO ESKD PATIENTS

HOUSING SECURITY

9% FINANCIAL ASSISTANCE TO AVOID EVICTION OR FORECLOSURE

BASIC NEEDS

20% HELP PAYING FOR UTILITIES TO ENSURE ELECTRICITY, WATER OR GAS AREN'T DISCONNECTED, AND OTHER OTHER ESSENTIAL EXPENSES

FOOD SECURITY

71% GROCERY STORE GIFT CARDS TO ENSURE FOOD SECURITY

Image Source: Tennessee Kidney Foundation

ACCESS TO CARE: MEAL DELIVERY PROGRAM

JULY 1, 2023 - JUNE 30, 2024

10 CLIENTS ENROLLED IN PROGRAM

APRIL-JUNE 2024

TOTAL MEALS PROVIDED:
840

Image Source: Tennessee Kidney Foundation

TENNESSEE KIDNEY FOUNDATION

How do program clients apply for TKF programs?

TKF works collaboratively with social workers at 63 dialysis clinics within our 42-county service area who make referrals for our programs. Social workers submit annual applications for patients who qualify for our programs, and TKF staff review and approve these to ensure all criteria are met. The social worker then submits a request for the program to which their patient is interested in being enrolled either monthly or as needed.

Who qualifies for TKF assistance programs?

- Program participants must live within the 42-county TKF service area or receive dialysis/transplant care within the service area.
- Dialysis patients and transplant candidates or recent recipients may qualify if they are at or below 200% of the federal poverty level for income and do not have insurance benefits that provide the services offered by TKF.
- TKF has a limited budget for assistance programs, and we currently have a waiting list for new applicants.

TENNESSEE KIDNEY FOUNDATION

Community Outreach and Education Programs

Kidney Health Screening and Education Events
Free screening events that include height, weight, blood pressure and urinalysis, followed by a one-on-one conversation with a healthcare professional who reviews the results and makes recommendations for next steps.

Virtual education sessions can be provided for corporate audiences, patients, family members, or community members about general or specific aspects of kidney health.

In 2024, more than 70% of participants in screening events have abnormal results for blood pressure, urinalysis, or both. Follow-up resources provide critical tools for participants to manage their health.

TENNESSEE KIDNEY FOUNDATION

Community Outreach and Education Programs

Social Worker Roundtables
TKF hosts bimonthly meetings at the TKF offices/virtually open to all Middle Tennessee transplant and dialysis social workers and clinic staff with relevant presentations by guest speakers, continuing education credits, and discussions about programs.

TKF TENNESSEE KIDNEY FOUNDATION

Community Outreach and Education Programs

Kidney Transplant Education

Education about the kidney transplant process and support for overcoming any barriers to care are provided for both potential donors and recipients. Information is shared at each community health screening and education event, on TKF digital platforms, via quarterly patient newsletters, and as needed when community members request information. TKF maintains close partnerships with St. Thomas West Kidney Transplant, Vanderbilt Kidney & Pancreas Transplantation, and the VA transplant center to provide necessary resources and fill gaps in service.

TENNESSEE KIDNEY FOUNDATION

Community Outreach and Education Programs

Health Equity Roundtables

TKF hosts semi-annual hybrid meetings at the TKF offices/virtually with healthcare professionals, community representatives, and public health experts to discuss pressing issues and solutions to improve TKF programs. The current health equity roundtable cohort is exploring the topic of empowering patients to be active participants in their health journeys, including improving doctor-patient communication and increasing patients' confidence during these interactions.

Patient Focus Group

CKD and ESKD patients in the cohort meet quarterly to confidentially discuss their health journeys related to kidney disease, dialysis, and/or transplant. Incentives are provided to participate, and all information shared is de-identified prior to compiling and studying. Results help define resources and tools to be provided to other patients to help improve their health outcomes and experiences with healthcare providers.

ESKD = end stage kidney disease

PROGRAMMATIC EVENTS

JULY 1, 2023 - JUNE 30, 2024

4 INFORMATION TABLE EVENTS

Senior Expo Cookeville, Lunch and Learn with Dorothy Marie Kinnard Foundation, VUMC Healthcare Day, Fisk University

1 ROUNDTABLE EVENT

Everyday Hero Roundtable Event

2 EDUCATIONAL EVENTS

Vine Studio Apartments & FunFitness Dance Exercise Event

1 VIRTUAL EDUCATION

Advance Financial

5 LOBBY DAYS

Fresenius West (2), DCI Mt. Juliet, US Renal Care Gallatin,

9 SCREENINGS

Mt. Zion (2), Greater St. John Missionary, Amazon, Lunch and Learn with Dorothy Marie Kinnard, Legislative Screening, TSU, and Hillcrest Church of Christ

Image Source: Tennessee Kidney Foundation

VUMC = Vanderbilt University Medical Center
TSU = Tennessee State University

COMMUNITY EDUCATION AND SCREENING EVENTS

JULY 1, 2023 - JUNE 30, 2024

FAITH CENTERS

Mount Zion Baptist Church Antioch
Mount Zion Baptist Church OHB
Greater St. John Missionary Church
Hillcrest Church of Christ

CORPORATIONS

Advance Financial
Amazon
Calliditas Therapeutics
DaVita
Tennessee Donor Services

UNIVERSITIES

Fisk University
Meharry Medical College
Tennessee State University
Vanderbilt University

COMMUNITY PARTNERS

Dorothy Marie Kinnard Foundation
FunFitness Dance Excersise Event &
Lunch and Learn
Senior Expo Cookeville

DIALYSIS CLINICS

Fresenius West
DCI Mt. Juliet
US Renal Care Gallatin
DaVita White Bridge

RESIDENTIAL PARTNERS

Vine Studio Apartments and two additional MDHA properties

Image Source: Tennessee Kidney Foundation

OHB = Old Hickory Boulevard
MDHA = Metropolitan Development and Housing Agency

BEYOND THE CORE
EDUCATION & PREVENTION

Upcoming Events:

September 25- Calliditas Healthcare Hero Dinner, 6:00-7:30pm

October 1- Health Equity Roundtable, 2:00-3:00pm

October 3- Food for Thought Social Worker Luncheon, 11:30am-12:30pm

October 16– DaVita Corporate Office (screening), 11:30am-3:30pm

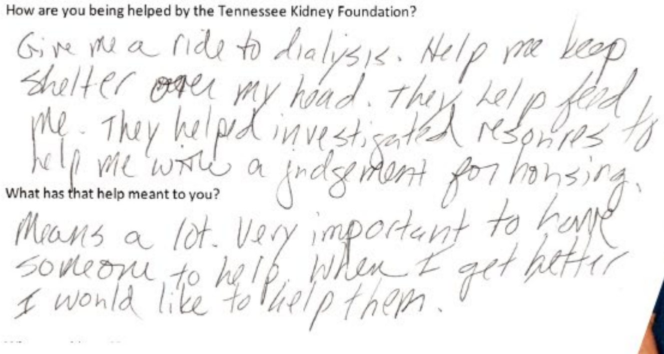
October 29- Cookeville Senior and Caregiver Expo (screening), 9:30am-2:30pm

October 30– Donelson Senior Center Educational Presentation, 11:30am-12:30pm

November 18- Thrive 55+ Ashland City Presentation, 11:00am-12:00pm

December 7 – At Your Pace Kidney Walk, 9am to 11am, Shelby Park (Nashville)

*volunteers needed for all events

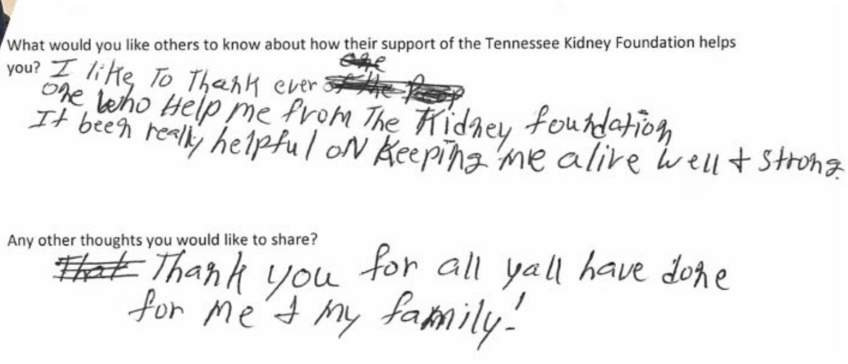


How are you being helped by the Tennessee Kidney Foundation?

Give me a ride to dialysis. Help me keep shelter over my head. They help feed me. They helped investigated resources to help me with a judgement for housing.

What has that help meant to you?

Means a lot. Very important to have someone to help. When I get better I would like to help them.



What would you like others to know about how their support of the Tennessee Kidney Foundation helps you? I like To Thank ever~~one~~ ~~of the Peop~~ one who Help me from The Kidney foundation It been really helpful oN Keeping me alive well + strong.

Any other thoughts you would like to share?

~~That~~ Thank you for all yall have done for me & my family!

Image Source: Tennessee Kidney Foundation

Let Us Hear From You

Pt. 3

Questions and Answers

Social Media

- **Instagram**
  @ESRD_NCC
- **Facebook**
  @ESRD.NCC
- **X**
  @ESRDNCC

Share your Patient Summit experience on social media!

- Use event hashtags on Instagram, X, and Facebook.
  - **#ESRDChamp**
  - **#TopOfThePodium**
- Tag the NCC's account so we can repost your content.

Thank You

SCAN ME

Complete the Post-Event Evaluation:

1) Open the camera on your cell phone
2) Point and scan QR code
3) Access link and complete post-event evaluation

All attendees will receive an email with the evaluation link and CEU information immediately following this call.

Contact NCCInfo@hsag.com if you need assistance.