

Breaking FREE

Living Well With
Kidney Disease

A publication of MedStar Georgetown Transplant Institute

Summer 2019 Vol. 1 No. 1



A NEW LEASE ON LIFE

Kidney transplant gives
the gift of quality time



MedStar Georgetown
Transplant Institute

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Welcome

A MESSAGE FROM MATTHEW COOPER, MD



Welcome to the first edition of our **Breaking FREE** newsletter. We hope this new publication will provide information that is both useful and empowering on your journey to a healthier life.

For people who receive dialysis, there are many reasons to be optimistic about the future. Thanks to advances in medical science, as well as many innovations introduced by MedStar Georgetown Transplant Institute, most dialysis patients are now good candidates for

transplants. Today, we accept patients who were not considered eligible even a few years ago, including those with certain chronic diseases or highly sensitive immune systems. We have remarkable new techniques and drugs to prevent organ rejection. And we have developed new practices that expand the pool of potential donors, living and deceased, to help those who cannot easily find a compatible living donor.

For example, a friend or family member no longer needs to give a kidney directly to you. Through a process known as paired kidney exchange, multiple donors are "paired" with matching recipients to help more people receive a life-saving living donor kidney.

The formula for a successful kidney transplant relies on strong three-way collaboration and communication among patients, the dialysis center staff, and our MedStar Georgetown transplant team. Your role is to ensure you are evaluated for the transplant so that you can get on the waitlist if you are eligible, and to keep yourself as healthy as possible while you wait. This includes attending all of your scheduled dialysis appointments, taking all your prescribed medications, and eating a healthy diet. Your dedicated and highly trained dialysis clinical care team—physicians, technicians, dietitians and social workers—will help educate and guide you. They will also inform us of any changes in your health.

Along with information about the transplant process, donor options, and tips for staying healthy, each issue of **Breaking FREE** will include stories about patients who have traveled the same path as you and are now enjoying a better quality of life. We hope their words will be a source of inspiration.

Remember, dialysis is an important but usually temporary step on the road to recapturing good health. Your future can be bright and all of us—your dialysis clinicians and the MedStar Georgetown transplant team—are here to help.

Matthew Cooper, MD

Director, Kidney and Pancreas Transplantation
MedStar Georgetown Transplant Institute



TO LEARN MORE about Dr. Cooper and MedStar Georgetown Transplant Institute, please visit MedStarGeorgetown.org/CooperVideo or call 202-444-3701.

Q&A for Patients on the Transplant Waiting List



Q HOW LONG WILL I HAVE TO WAIT FOR A NEW KIDNEY?

Wait time for a donor organ depends on several factors. These include your blood type, tissue matching, presence of preformed antibodies that could lead to organ rejection, and the time you have been receiving dialysis.

Expected patient waiting times also vary depending upon your geographical location within the United States as well as the local Organ Procurement Organization (OPO).

Wait times are calculated from the day you start dialysis (not the date you completed your evaluation). If you are listed before you start dialysis, your time will calculate from your date of listing. **Having a living donor can significantly shorten your wait time.**

Q HOW OFTEN SHOULD I EXPECT TO BE IN TOUCH WITH THE TRANSPLANT CENTER?

We typically like to see patients once a year while on the waitlist so that we can keep updated on medical issues that might affect getting a transplant.

For patients with more significant medical history, we may see you as frequently as every 6 months.

While we may only be in touch with you every 6 to 12 months, you should always feel free to contact us at **202-444-3701**.

Q WHAT DO I NEED TO LET THE TRANSPLANT CENTER KNOW ABOUT?

We would like to hear about any and all significant changes to your medical condition:

- Any time you have surgery
- Any time you require an overnight hospital stay
- Any abnormal screening tests ordered by your primary care provider



- When in doubt—call us! We would rather hear too much than too little.

We want to know about any change in your contact information:

- Any time you move or change your phone number
- Any change in your dialysis center
- Any change in your nephrologist or primary care doctor

We want to know about any change in your insurance information:

- When you change insurance plans, we need to make sure that you still have coverage for all the needed post-transplant medications.

If you are having elective surgery of any kind, you should let us know before the surgery happens.

Q WHAT TESTING IS NEEDED WHILE I AM ON THE WAITLIST?

- Annual testing for Hepatitis and other viruses
- Monthly blood testing

We need a sample of blood sent to our lab every month you are on the list. We use this blood to test you against the donor kidneys to make sure you are a match. If we do not have blood from you, we cannot test the kidneys, and you will not be offered a transplant. If you are on dialysis, your dialysis center should be taking care of this. Be sure to check that this is being done.

- Annual chest X-ray and electrocardiogram
- Repeat heart testing (a stress test and an echocardiogram) every 2 years
- You must keep current with standard screening tests including (as appropriate) pap smears, mammograms, colonoscopies, and prostate-specific antigen (PSA) testing.
 - PSA tests should be updated yearly (men over 50)
 - Mammograms should be updated every 1 to 2 years (women over 40)
 - Pap smears should be updated every 2 to 3 years (all women)
 - Colonoscopies should be updated every 5 to 10 years (all patients over 50)

Q HOW DO I FIND A LIVING DONOR?

A living donor transplant can decrease the time a patient waits to be transplanted and can provide a better quality organ. The kidney will usually work immediately after surgery and the patient will experience fewer episodes of rejection. Any healthy person can be a kidney donor. The donor does not need to be a family member. The donor can be a friend, acquaintance, spouse, in-law, or even a stranger.

In addition, through a process known as paired kidney exchange, multiple donors are “paired” with matching recipients to help more people receive a life-saving living donor kidney.

The donor must be:

- At least 18 years old
- Appropriate candidate for general surgery
- Meet certain medical, social, and psychological criteria
- Able to give informed consent

To learn more, contact us at 202-444-3701.

A New Lease on Life

Washington, D.C., resident John Bayton had been feeling “off” all summer. Tiredness, mild headaches, and difficulty keeping food down made him think he had the flu. He went to his primary care doctor, who did some tests to learn the cause of the symptoms.

“When I called to get my test results, my doctor told me to go to the emergency room immediately because my kidneys were failing,” he remembers. “Two or three hours later, I started dialysis. It was an unexpected turn of events. No one in my family had kidney disease, I wasn’t diabetic, and didn’t have high blood pressure.”

That was 2003 and marked the beginning of John’s journey through the world of kidney disease and dialysis. During the next seven years, he received several different types of dialysis in different settings, including hemodialysis in the hospital and outpatient peritoneal dialysis.

In 2009, he received his first kidney transplant, but went into rejection in 2016, which meant going back on dialysis. He went on the transplant waiting list at The Johns Hopkins Hospital and MedStar Georgetown Transplant Institute at the encouragement of his nephrologist, who felt being on two lists would improve his odds.

He tried several more approaches to dialysis, starting with in-center hemodialysis. However, that approach took a toll on John’s lifestyle and finances, since he spent so much time away from home and work. He then switched to in-center nocturnal dialysis, where he slept at the dialysis center and received his treatments overnight so he could maintain as normal as possible a schedule during the day. This worked well for him for a while.

But John decided to explore at-home dialysis; learning all he could, he thought it was a good option for him. Following a month-long training program “I was finally able to do dialysis in the comfort of my own home, removing the need to travel to a clinic. In addition to being more convenient, it allowed me to become more involved and accountable for my treatment,” he says.

In February 2019, MedStar Georgetown Transplant Institute surgeon Peter Abrams, MD, performed John’s second kidney transplant, using a deceased donor kidney. “The experience went very smoothly,” John adds. “All my care has been well coordinated with my nephrologist and my primary care doctor. The MedStar transplant team have been awesome; they’ve become family. I have felt supported and informed through every step of the process and the care I have received has been extraordinary.”

Now that he’s no longer on dialysis, John’s life has changed markedly for the better. He says, “I’ve been really living again. I’ve accepted a new job, traveled, represented my fellow kidney patients at four conferences, made new friends, started working out again, and had the best Capital Pride weekend ever! The smile on my face says it all. I’m just getting started!”

One of the activities he’s able to spend more time on since his transplant is expanding his advocacy efforts and sharing his experience as a kidney disease patient with other patients and physicians. He’s an active member of several kidney disease patient groups on Facebook, LinkedIn, and Twitter, where he shares his experiences and encourages his fellow patients to talk to their medical teams openly and honestly. He’s also gone back to the facility where he used to undergo nighttime dialysis and talked with patients about the many different options available. He plans to return to talk with patients on daytime dialysis, as well.

As a vocal advocate for patients with kidney disease, he’s taken part in the American Kidney Fund Capitol Hill Day, where he met with Congresswoman Eleanor Holmes Norton and talked about raising awareness of kidney disease. To help educate patients about their options, he’s working with



Social Media Groups and Other Online Resources

The first step to advocating for yourself is to learn about your disease, treatment options, and the experiences of other patients. The following websites can supplement your discussions with your medical team and provide access to support communities.

The National Kidney Foundation (*Kidney.org*) offers peer support and educational information as well as community events.

The Renal Support Network (*RSNHope.org*) has a robust online/telephonic support community.

KIDNEY TRANSPLANT GIVES THE GIFT OF QUALITY TIME



“
THE SMILE ON
MY FACE SAYS
IT ALL. I’M
JUST GETTING
STARTED!”



WOULD YOU LIKE TO
SHARE YOUR STORY?
Contact Lisa Arrington at
lisa.t.arrington@medstar.net

ESRD (End-Stage Renal Disease) Network 5, a non-profit that oversees policy structures and patient grievances related to dialysis centers in Virginia, West Virginia, District of Columbia, and Maryland, which has given

him the chance to help develop new resources for patients.

“What I learned through all my experiences is that there is no one-size-

fits-all solution,” John reiterates. “You need to do research to understand all your options and, if something doesn’t work for you, speak up and advocate for yourself with your medical team.”

United Network for Organ Sharing (UNOS.org) manages the national transplant waiting list, matching donors to recipients.

MedStar Georgetown Transplant Institute (Medstargeorgetown.org/kidney) includes patient stories, videos and support group meetings.

The Scientific Registry of Transplant Recipients (SRTR.org) is an excellent tool for patients trying to choose a transplant center based on outcomes data and also provides information on the general transplant system in the U.S.

We also recommend that you search for online communities via **Facebook, Twitter, Instagram, and YouTube**. If you don’t find what you want, consider creating YOUR OWN online community using these digital platforms.

Considering Transplant?

HOW IT WORKS

Patients with kidney disease begin the evaluation process by visiting MedStarGeorgetown.org/KidneyRecipient. For questions, call **202-444-3701**. The evaluation can take a full day, and we encourage you to bring a support person.

The entire pre-transplant evaluation, including imaging and lab studies, can be accomplished at any of our eight convenient sites, but the renal transplant surgery is performed at MedStar Georgetown University Hospital. (See map on back cover.)

The pre-transplant team includes surgeons, nurses, nephrologists, social workers, financial counselors, and dietitians. The evaluation determines whether you are medically eligible to receive a transplant and whether there

are any psychological or social barriers to a successful outcome. The goal is to be certain that your health status is optimal, you can be transplanted safely, and you can take good care of your new organ.

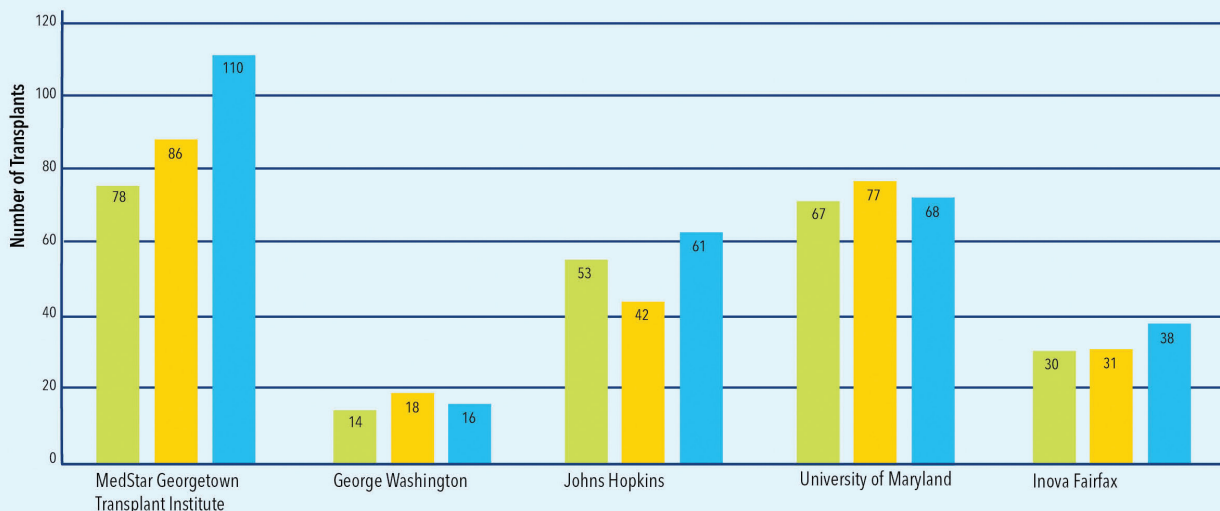
You will also meet with each member of the pre-transplant team, who will carefully explain the process as well as your responsibilities. You will learn about live-donor organ donation and discuss opportunities to identify a living donor.

The entire team meets weekly to share information and make recommendations. They will quickly notify you, your nephrologist, and your dialysis team of their decision. If you are put on the waitlist at MedStar Georgetown Transplant Institute, you must continue to manage your condition so that you remain healthy enough for the transplant. All patients who qualify for renal transplant are placed on a waiting list for a deceased organ, even if a potential living donor is available.

Experience Makes a Difference in Outcomes

MedStar Georgetown Transplant Institute has performed more living donor kidney transplants than any other center in the region.

Living Donor Kidney Transplants in the D.C. Area



2016 2017 2018 Source: UNOS.org/data accessed Jan 2019. MGTI (DCCH + DCGU)



MedStar Georgetown Transplant Institute Team

The Transplant Evaluation Process

The first step toward receiving a transplant is to be referred by your primary care doctor, nephrologist, or dialysis nurse, or for you to contact us directly. Then, the evaluation process begins.

This evaluation includes the following:

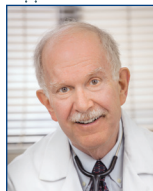
- 1 Initial education program** about the benefits and details of kidney transplantation
- 2 Interview with one of our transplant nephrologists** to answer your questions about transplant
- 3 Review of your medical history**
- 4 Physical examination**
- 5 Psychosocial evaluation** with a transplant social worker to address your support needs following transplant
- 6 A meeting with our financial counselor** to make sure you are fully covered for your post-transplant expenses
- 7 Blood tests** for tissue typing and antibody screening
- 8 Information** for you on benefits of living donation and contact information for any interested donors
- 9 Consultations with various specialists** to make sure transplant is a safe option for you
- 10 Presentation to our multi-disciplinary pre-transplant committee** for final review and approval of your transplant candidacy

Additional testing may be required, depending on your individual needs.



Visit MedStarGeorgetown.org/KidneyRecipient to make an appointment for an evaluation.

Jack Moore, MD,
Medical Director of the Kidney Transplant Program at MedStar Georgetown Transplant Institute at MedStar Washington Hospital Center



Unlike in earlier years, after a careful evaluation we are now saying yes to most patients. Therefore, there is good reason for a person to approach the process with optimism.

I sit down with patients and ask them what their lives are like now and what changes they expect after a transplant. We have an honest and intimate exchange, not only about their history, but also about realistic expectations for life after the surgery. If they decide they want the transplant, I present their story to the selection team, along with my professional recommendation. Each person who sees the patient will give an assessment to the committee. Everyone's voice is critical and equal. Whether we approve or decline the transplant, we are always working in the best interest of our patients.



Alexandra Radomsky, MSW, LICSW,
Clinical Social Worker, MedStar Georgetown Transplant Institute

While a kidney transplant most often transforms a patient's life in very positive ways, it also presents some unique changes and challenges. Part of our role as social workers is to help patients prepare for those. The patient's social support system is very important for success. We want to be sure they have someone to lean on physically and emotionally before, during, and after the transplant. We ask that this person come with the patient to appointments—including the initial evaluation meeting. For those patients who do not have a spouse, friend, or family member, support may be available from their spiritual community, a co-worker, or other social connection. We help patients brainstorm these alternatives.

The social work team also helps patients evaluate whether they are committed to the process: coming to appointments, getting blood work done, taking medications, changing their diet. Much of the responsibility for success is in the patient's hands.

And finally, we assess the patient's psychosocial history, ensuring there is no current drug or alcohol abuse and that he or she has the inner resources to cope. We are always willing to work with patients to ensure they become good candidates for the surgery.

Focus on Protein

NUTRITION TIPS



Diet plays a vital role for patients with kidney disease. Following a renal diet while receiving dialysis can make a difference in how you feel by controlling the buildup of waste products in the blood. Patients on a renal diet must limit their potassium, sodium, fluid, and phosphorus intake. Protein, an essential nutrient, is lost during each dialysis treatment, so patients must consume high amounts of protein to replace it.

The best protein is from animal sources such as beef, fish, chicken, eggs, and turkey. Dairy products such as milk, cheese, and yogurt are also good protein sources, but should be limited because of their high phosphorus content. Processed meats such as deli meat, bacon, hot dogs, and sausage should be avoided since they are high in sodium.

Below are some ways to increase your protein intake:

- Eat high protein food first, before other foods
- Snack on foods such as chicken, egg, or tuna salad on crackers
- Eat renal-friendly, high-protein bars (ask your dietitian for recommendations)

OVEN BAKED TILAPIA WITH SAUTEED VEGGIES



INGREDIENTS:

- ½ large onion
- 1 3-ounce tilapia fillet
- 2 lemon wedges
- Salt-free spice mix
- 1 cup fresh sugar snap peas
- ½ cup bell pepper mix, julienne cut
- ½ cup cauliflower florets
- 1 tablespoon olive oil

Preheat oven to 350 degrees. Cover a baking sheet with aluminum foil and spray with nonstick spray. Cut one thick slice of onion, set on baking sheet. Put tilapia fillet on top of the onion and sprinkle with your choice of sodium-free spice mix (such as crushed red pepper flakes or fresh ground black pepper). Squeeze lemon wedge over fish and leave the wedge on top of the fish while baking. Bake for 10 to 12 minutes or until white and flaky.

While fish is baking, heat oil in a skillet over medium-high heat. Sauté sugar snap peas, bell peppers, and cauliflower. Season with sodium-free spice and squeeze a lemon wedge over veggies.

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D. MedStar Southern Maryland Hospital Center
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F. MedStar Georgetown Transplant Institute in Annapolis
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G. MedStar Franklin Square Medical Center
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Ellicott City, MD 21042

MEDSTAR GEORGETOWN TRANSPLANT INSTITUTE makes it convenient for patients to be evaluated for transplantation. We are now evaluating kidney and pancreas transplant candidates at eight convenient locations.

Visit MedStarGeorgetown.org/KidneyRecipient to make an appointment for an evaluation.

