

2020 UPDATE

FIGHTING KIDNEY DISEASE

together



NATIONAL KIDNEY
FOUNDATION®

New England

National Kidney Foundation

209 West Central Street, Suite 220
Natick, MA 01760

508-907-6030
NKFNE@kidney.org

We're fighting kidney disease.

Here's how.



The National Kidney Foundation is the leading organization in the U.S. dedicated to the **awareness, prevention and treatment** of kidney disease. We provide a broad array of programs, resources, and services for patients, those at risk, healthcare professionals and the general public.

THE BIG ASK, BIG GIVE

Living donation makes better lives possible. Whether you need a kidney, or want to learn more about donation, it starts with asking the National Kidney Foundation.

For more information, contact **Stacey Senat** 508.907.6030 ext. 333 or Stacey.Senat@kidney.org.

ADVOCACY

The NKF empowers those affected by kidney disease to become advocates for themselves and others, by giving them tools to communicate with lawmakers, share their stories, and raise awareness. Learn about our NEW Advocacy Program and share your voice! For more information, www.kidney.org/advocacy

PROFESSIONAL EDUCATION, TOOLS & SUPPORT

NKF provides opportunities for collaboration, networking, and career advancement for every member of the kidney patient care team. Tools and resources, based on NKF-published guidelines, are developed for professionals to incorporate into their practices and advance patient care.

KIDNEY KUISINE COOKING PROGRAM

Kidney Kuisine is a free interactive cooking class for patients and their caregivers. Each class creates a cooking experience where participants recreate an authentic meal to be more kidney friendly by substituting ingredients. For more information, contact **Stacey Senat** 508.907.6030 ext. 333 or Stacey.Senat@kidney.org.

NKF CARES

The NKF Cares Help Line offers free support for patients, families, and caregivers affected by kidney disease.

Call **855.NKF.CARES (855.653.2273)** or email nkfcare@kidney.org to speak with a trained professional who will answer your questions, listen to your concerns, and send you free education brochures. We offer support and resources in both English and Spanish.

NKF PEERS

NKF Peers is a free, telephone-based program offered to stage 4 kidney patients, those on dialysis or those with a transplant. Patients are linked with trained volunteer mentors who offer support and guidance. For more information, call **855.NKF.PEERS (855.653.7337)** or email nkfpeers@kidney.org.

KIDNEY HEALTH INFORMATION

The National Kidney Foundation (NKF) has the most extensive library of kidney health information for individuals, patients, transplant recipients, and living donors, including newsletters, printed brochures and online materials.

KIDNEY PATIENT PROGRAMMING

NKF New England partners with area hospitals, institutions, and community organizations to deliver kidney health and awareness programs. We offer education through live, interactive events, as well as online programs and information. Watch our local webpage kidneyhealth.org for upcoming programs or for more information, contact **Stacey Senat** 508.907.6030 ext. 333 or Stacey.Senat@kidney.org.



**National
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For more information regarding our local programs and services, please contact Stacey Senat, Program Manager at 508.907.6030 ext. 333 or Stacey.Senat@kidney.org.

amy



What would you do if at 16 your pediatrician said you have polycystic kidney disease and you will need a transplant by the time you're 45? If you are anything like Amy Brooks, you would "worry about that later". Later came quickly for Amy, as high blood pressure, anemia, chronic fatigue and finally kidney failure kicked in. As predicted on her 45th birthday Amy was put on the nationwide cadaver donor list, which she was told she'd be on for years because her antibodies made her an extremely difficult match. Heavy hearted, she

went home to ready to go out with friends, a night that would change her life forever. Knowing of Amy's declining health, each woman spoke up lamenting how they wish they could help. Then Sandra arrived. And in her thick Watertown accent said, "oh Blondie! I'll give ya a kidney!" What unfolded next gave her doctor's pause. Sandra turned out to be Amy's one in a million "perfect match". Within months the two women were in adjoining operating rooms and underwent an extraordinarily successful kidney transplant. Sandra was released in 2 days with one kidney and Amy was out in 6 with the other. The two women feel that this is their journey, attending charity events together and speaking up on behalf of kidney donation. **Thanks to Sandra's incredible gift, Amy is completely free from disease and pain and is living her best life as an amazing healthy mom. Thanks to Sandra, Amy has her life back.** ■

matt

I was born in 1985 with Posterior Urethral Valves, which substantially and permanently damaged my kidneys. Growing up, I was luckily able to live a pretty normal life with minimal restrictions, but I still knew there was something different about me compared to my peers. Around my teens, I figured "Well, I may as well get involved with the National Kidney Foundation." Go to the walks, get a t-shirt, etc. As a kidney patient, it seemed like the right thing to do. But as my condition intensified in my 20's and 30's and I began getting prepped for a transplant, working with the NKF became a necessary thing to do. The foundation came through with invaluable resources for me — directly connecting me to other kidney patients who had been through what I was about to go through, and also opening my eyes to forums and networks where I could ask (and answer) questions about kidney failure, transplantation, etc. They were also a source of support for my kidney donor — my younger sister, Emily.



There are a lot of unknowns heading into a process like this, and having a positive and informed resource available to shepherd you through it is priceless to have. ■



tishawna

PAINTING THROUGH DIALYSIS TREATMENTS

In 2012 Tishawna was a 26-year-old recent graduate of RI College, pregnant with her second child. She was excited about welcoming a new baby. Unfortunately, she developed complications during the pregnancy including gestational diabetes. Her health and pregnancy were monitored very closely for months. At eight months the situation became dangerous. Her baby was delivered a month early to protect both the mother and baby. The baby did well and Tishawna was recovering from the birth and was a busy mother of 2. In 2013 Tishawna became a CNA (Certified Nursing Assistant) and was juggling a new job and caring for two young children. A short time later, Tishawna's GFR was concerning her physicians. After seeing a Boston Nephrologist, she was put on medications to help protect her remaining kidney function.

In 2015, Tishawna's GFR continued to decline. It was then that she had her first dialysis treatment. As time went on, and she became accustomed to the routine of dialysis, she developed close relationships with other patients at her dialysis center. There was a tight bond between the patients through the shared experience. There were 40 patients

when she started on the treatment. Over the years, 25 of those 40 patients passed away. The losses were a very difficult thing for Tishawna to experience. Many of those patients were much older than Tishawna. This made her feel like she had a disease for older people – but she was a young mother. How could this have happened to her? She should be out and about and enjoying her young babies.

During the 4 years of dialysis treatments, Tishawna looked for ways to pass the time and to deal with her feelings about kidney disease, patient deaths, and the treatments that kept her alive. When she was younger, she had painted as a hobby. She decided to take up the painting again to fill the time she was tied to the machine. She put her thoughts and feelings into her paintings. Some of her paintings were about life in general and the beauty of life experiences. Others showed her complicated feelings about life sustained by machines, and time, and hope.

In 2019, Tishawna reached out to the NKF to talk to staff about how she wanted to share her feelings through her paintings. It was her hope that sharing her story and art would help other kidney patients. Shortly after the conversations began, Tishawna received her transplant and is doing very well. **She hopes that sharing her art with others will help in providing hope and a sense of community to other kidney patients.** ■





National Kidney Foundation®

HealthUnlocked



The National Kidney Foundation
has a new online community
for people like you



The community encourages discussions on various aspects of kidney disease and health. Connect with other people dealing with the same issues.



Just like other social networks (think Facebook, Twitter, LinkedIn and Instagram), you can create your own profile page, like other people's posts, ask or reply to a question and follow other people.



The difference with HealthUnlocked is that you can network anonymously and connect with other people who are affected by kidney disease. On the community, you can talk about your health, symptoms, management and much more.

Join our community on HealthUnlocked, the world's largest social network for health

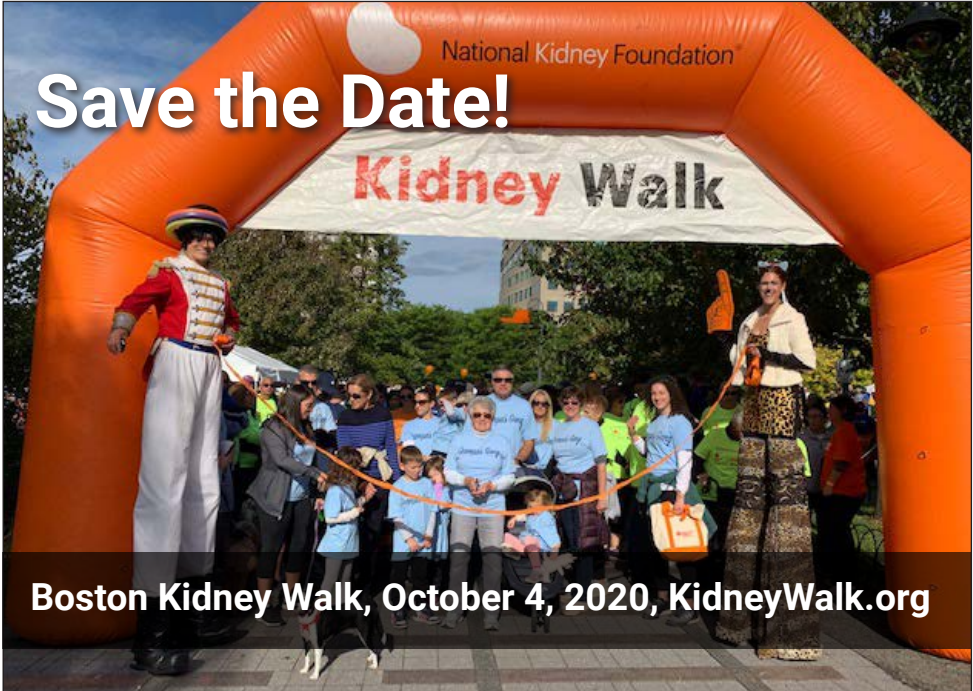
Dialysis: <https://healthunlocked.com/nkf-dialysis>

Early Stage CKD: <https://healthunlocked.com/nkf-ckd>

Living Donors: <https://healthunlocked.com/nkf-donors>

Transplant: <https://healthunlocked.com/nkf-kidneytransplant>

Parents of Children with Kidney Disease: healthunlocked.com/nkf-parents



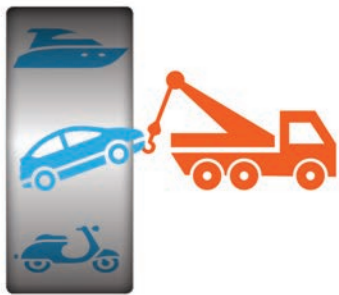
Save the Date!

National Kidney Foundation

Kidney Walk

Boston Kidney Walk, October 4, 2020, KidneyWalk.org

DONATE YOUR CAR
Quick. Easy. Free pick. *Vehicle*



Our name is *Kidney Cars* but we'll gladly accept any type of vehicle!
We'll turn it into life-saving programs...and you could turn it into a tax deduction!



**Kidney
Cars**

**KIDNEYCARS.ORG
800.488.CARS**

The National Kidney Foundation is a tax exempt, not-for-profit, 501(c)(3) organization.
All donations are tax deductible to the fullest extent of the law.

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HOW DO YOU FIND A KIDNEY DONOR?

If you have kidney disease and need a transplant, or you have a family member or friend in need, you may not know how to find a kidney donor. Many people won't get a transplant simply because they don't know how to share their story and ask people to consider donation. **We can show you how.**

WHY THINK ABOUT GIVING ONE?

You may want to know why people donate a kidney to someone. People everywhere are stepping up to help others live better lives... family, friends, even total strangers... maybe even someone close to you. **We can show you why.**

LIVING DONATION MAKES BETTER LIVES POSSIBLE.

Whether you need a kidney, or want to learn more about donation, it starts with asking the National Kidney Foundation.

kidney.org/livingdonation | 844.2BIGASK (844.224.4275) | bigask@kidney.org



National
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30 East 33rd Street
New York, NY 10016

#BigAskBigGive



michael

RECIPIENT & DONOR

genevieve

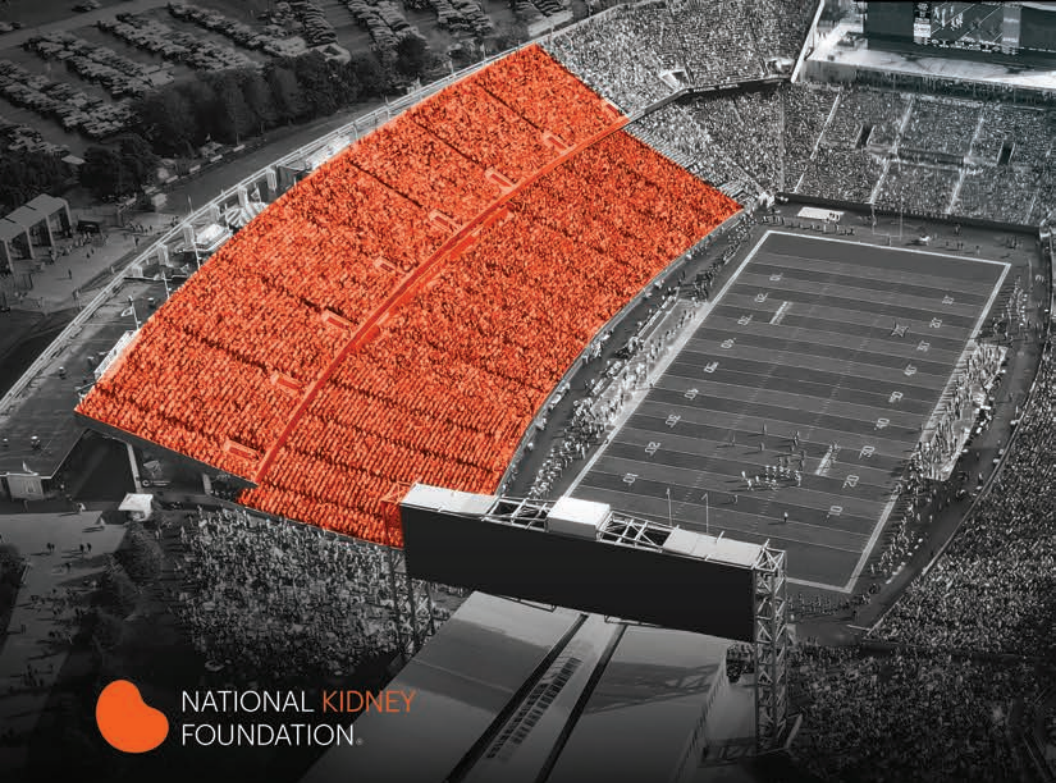
Michael: I was diagnosed in 2013 with polycystic kidney disease (PKD). With no family history of the disease and an otherwise clean bill of health, my diagnosis was somewhat of a surprise for an active guy in his late-twenties. As a high school biology teacher, I would frequently teach about kidney function, dialysis and kidney disorders, but I never suspected my own kidney story would become much more personal. My GFR ticked down slowly but steadily for a few years until I finally qualified to be listed on the National Kidney Registry in January of 2017. Unfortunately, my wait for a deceased kidney would be many years in Massachusetts because of my type O blood. I started looking for a kidney among family members and close friends, but there were no compatible matches. After a year of searching and watching my GFR tick down, in January of 2018 I took to social media to ask for a kidney. The results were totally

Continued

overwhelming. My Facebook post went viral, mostly being shared by friends, colleagues and former students. Over 60 potential donors from around the country came forward, but my eventual donor ended up being a friend who taught right down the hall named Genevieve.

“**Genevieve:** When you tell people you’re going to donate a kidney, the natural question is why. Not “Why would you do something so generous?” because I like to think most of us have an impulse to kindness — witness the response to Michael’s Facebook post. But “Why would you voluntarily submit to multiple medical tests, anesthesia, nights in the hospital, and weeks of recovery?” And at first, I couldn’t articulate my answer very well, especially the fact that while going through all those tests, and in all the days leading up to the surgery, all I felt was giddy anticipation. What I have come to see is that I had a second, personal goal in donating my kidney, beyond helping Michael. The entire journey proved to be a healing one for me as well, following the death of my mother just weeks before I saw that Facebook post. She had been sick, treated for cancer, cured of cancer, and then died suddenly, all in the space of one year. My path to donating a kidney became the happy mirror to the experience we had with my mother, and it ended not in darkness but in beautiful light. You don’t need to be recovering from trauma to donate an organ, but whatever impulse you bring, know that it will feel better than anything you can imagine.”

Michael: Our transplant happened in October of 2018, only nine months after I had posted that fateful Facebook plea for help. We’ve both recovered successfully, and still joke in school about the beautiful urine I now produce with Genevieve’s kidney. We’ve been using our platform as teachers to spread awareness about living organ donation both in school and in the wider Boston community through speaking engagements, volunteering for kidney awareness events and participation in recipient panels (Michael) and donor support groups (Genevieve). A message we consistently share with others is how effective social media can be in securing a donor. Even though Genevieve and I had known each other for years, it took a Facebook post to connect my need for a kidney to her desire to donate. Though an appeal to others for help on social media can be daunting and intimidating, social media can play a vital role in connecting donors and recipients together. **I’m forever grateful to my friend Genevieve for giving me the gift of life, and to social media for connecting us together in a profound way for the rest of our lives. ■**



NATIONAL KIDNEY
FOUNDATION

Wondering why one third of the stadium is orange? **Kidneys.**

33% of American adults are at risk for kidney disease. So in a packed arena, this many seats would be filled with all those at risk. Sadly, kidney disease is hard to spot, and often goes undetected. But don't worry, it only takes a minute to take our kidney quiz and find out where you stand.



ARE YOU
THE 33%?

Take the quiz at **MinuteForYourKidneys.org** to find out.

add meaning
**TO YOUR
MILES**



REGISTER FOR YOUR NEXT RACE AND
RAISE FUNDS AND AWARENESS FOR
THE NATIONAL KIDNEY FOUNDATION.



LEARN MORE AND GET STARTED!
GOTEAMKIDNEY.ORG



*There Are Two Roads from
New England to Pebble Beach.*

JUNE 9, 2020

Boston Golf Club, Hingham, Massachusetts

AND

SEPTEMBER 14, 2020

TPC Boston, Norton, Massachusetts



National
Kidney
Foundation®



KONICA MINOLTA
GOLF CLASSIC

England is proud to have two of the country's top venues in our annual NKF Konica Minolta Golf Classic family of tournaments. The top finishing teams in these two Classics will earn invitations to our National Finals at Pebble Beach Resorts in January of 2021.

A FREE INTERACTIVE COOKING CLASS FOR PATIENTS AND THEIR CAREGIVERS



Kidney Cuisine

AN INTERACTIVE COOKING CLASS

Kidney Cuisine is a free interactive cooking class for patients and their caregivers. Each class creates a cooking experience where participants recreate an authentic meal to be more kidney friendly by substituting ingredients.

For more info contact Stacey Senat:
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RECIPE

Fish Tacos with Lime Sauce

Makes 4 servings (2 tacos each)

INGREDIENTS

- 1 lb. tilapia
- 2 limes
- ½ cup mayonnaise
- 1 tsp. chili powder
- ⅓ cup all-purpose flour
- 2 tbsp. vegetable oil
- 8 6" flour tortillas
- 1 cup shredded cabbage
- ½ cup shredded carrot
- 1 fresh jalapeno, thinly sliced

DIRECTIONS

1. Rinse tilapia fish, pat dry with paper towels. Cut fish into 1-inch pieces.
2. For lime sauce, juice two limes over a small bowl. Stir in mayonnaise and chili powder.
3. Transfer ⅓ cup of the mayonnaise mixture to a medium bowl. Add fish; toss gently to coat. Discard the mayonnaise that raw fish was dipped in.
4. In a shallow dish, dip coated fish into flour.
5. Cook fish over medium heat in vegetable oil, in a large skillet. Cook for 2 to 4 minutes until browned.
6. Fill tortillas with fish, cabbage, carrots, and jalapeno. Drizzle with remaining lime mayonnaise

NUTRITIONAL ANALYSIS

Calories: 298

Total Fat: 9 g

Sodium: 380 mg

Carbohydrates: 26 g

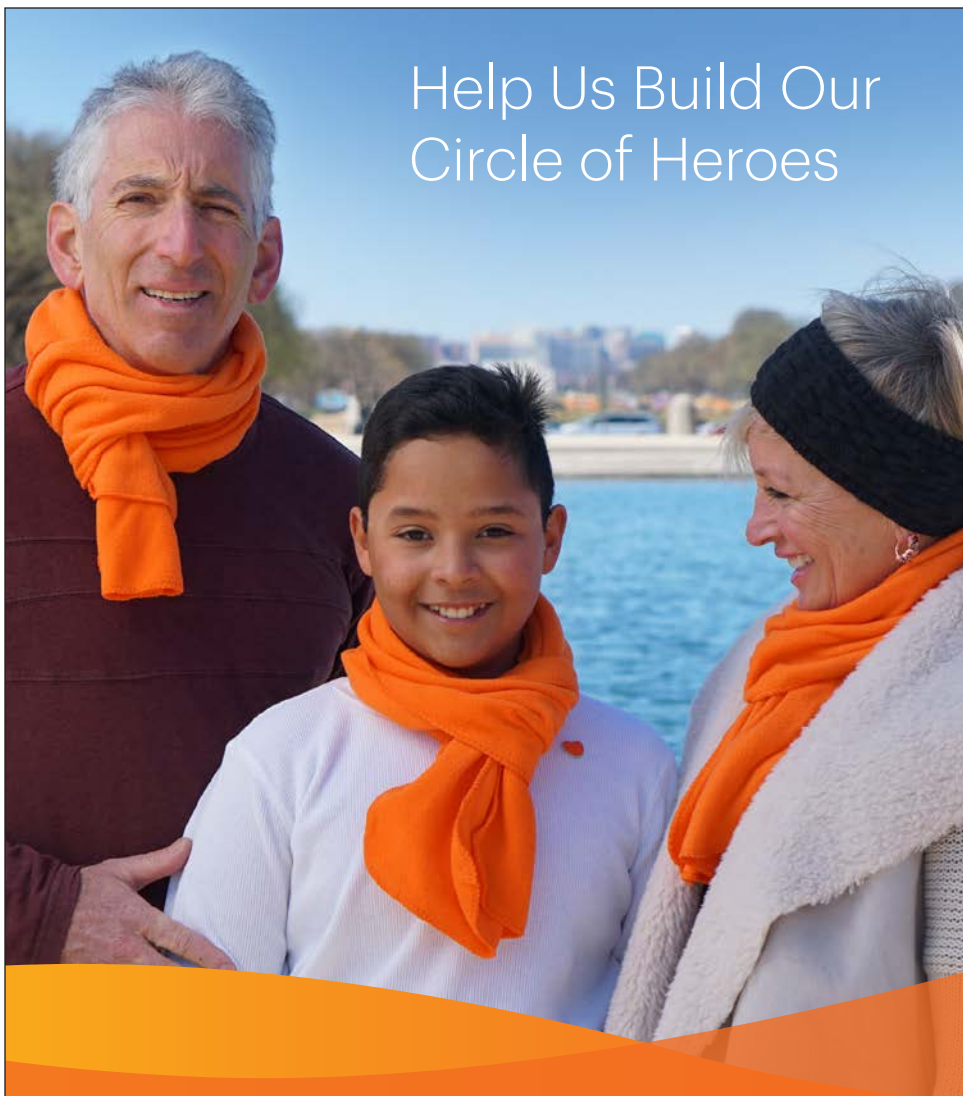
Protein: 27 g

Potassium: 440 mg

Phosphorus: 260 mg



Help Us Build Our Circle of Heroes



Join the National Kidney Foundation's Hero Circle and be part of a network of individuals who share a commitment to our life-saving mission.

Together, we change the lives of people affected by kidney disease.

Hero Circle members are individuals who invest a minimum unrestricted contribution of \$1,000+ or a monthly contribution of \$83.34. Want to join? Learn more at [kidney.org](https://www.kidney.org)



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