



AN INTRODUCTION  
TO FABRY DISEASE

7



WALKING IN  
THEIR SHOES

9



USING SOCIAL MEDIA  
FOR ADVOCACY

18

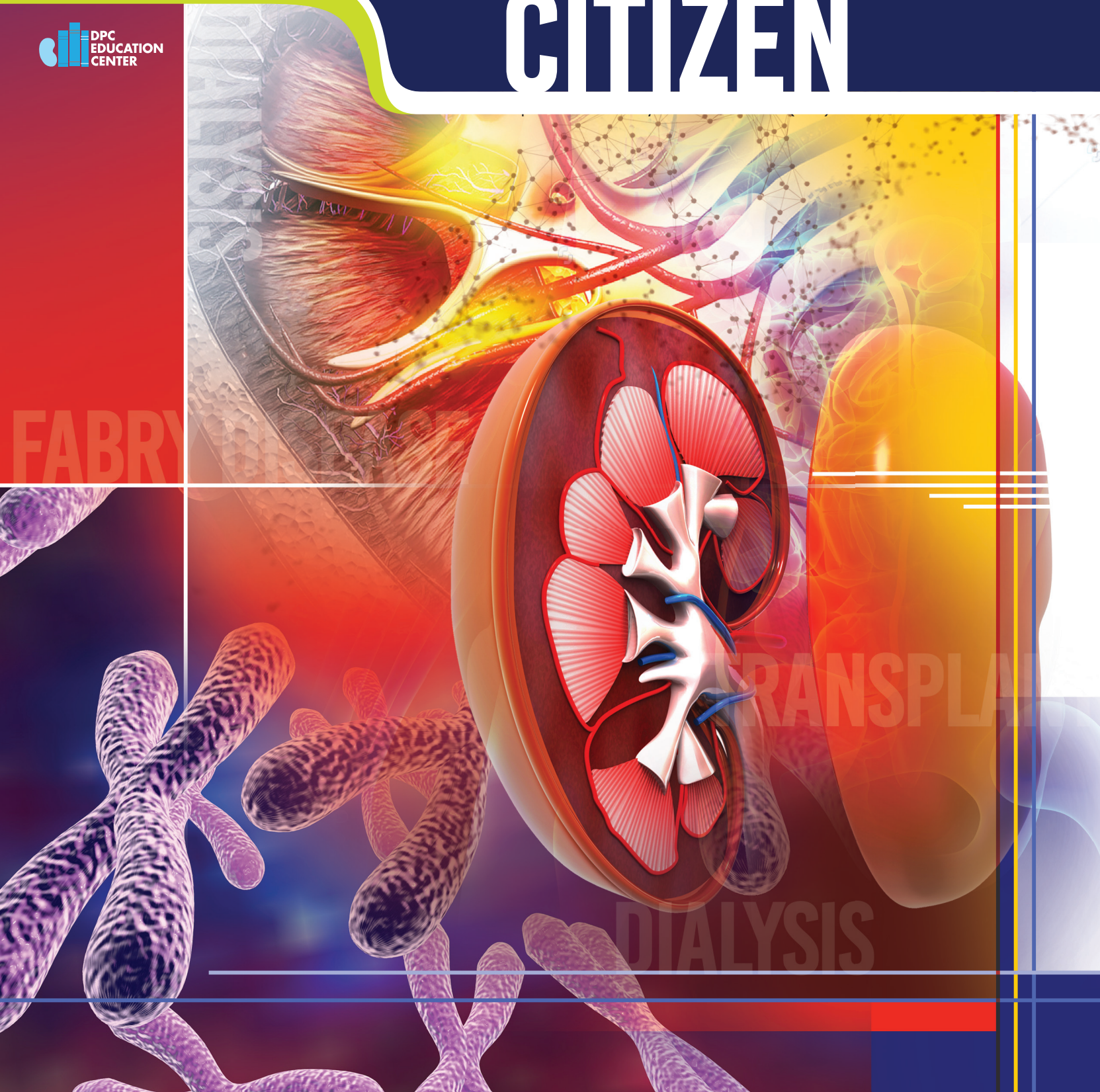
# THE KIDNEY CITIZEN

DPC  
EDUCATION  
CENTER

FABRY

TRANSPLANT

DIALYSIS





## Board Members

Nancy Scott  
President

Julie Crandall  
Vice President

Diane Brisbane  
Secretary

Mike Guffey  
Treasurer

Andrew Conkling

Danny Iniguez

Robert Lee

Jack Reynolds

## Advisory Council

Sandra Amaral  
M.D., M.H.S.

Akhtar Ashfaq  
M.D.

Laura Arentz  
M.B.A., M.S., R.D., L.D.N

Teri Bourdeau  
Ph.D.

Kerri Cavanaugh  
M.D., M.H.S.

Debbie Cote  
M.S.N., R.N., C.N.N., N.E.-B.C.

Steven Curtiss  
M.D.

Kerry Cooper  
M.D.

Stephanie Johnstone  
L.C.S.W.

Elizabeth Jones  
L.C.S.W.

Rajnish Mehrotra  
M.D.

Cheryl Neal  
M.D.

Velma P. Scantlebury  
M.D., FACS

Barry Smith  
M.D., Ph.D

Kathleen Smith  
B.S., R.N., C.N.N.

Joan Thomas  
M.P.A., C.E.M., A.B.C.P., M.E.P.

### Dear friends

In the age of the 24-hour news cycle, at the Dialysis Patient Citizens (DPC) Education Center we continue to look for the best ways to share the latest kidney disease news and information with you. Currently, we communicate on social media (namely Facebook), produce this newsletter in an easy-to-read online format, and share our education seminars online for viewing at your convenience. You probably noticed, we are integrating content relevant to you across all forms of media. Articles in the print issue of the Kidney Citizen may correspond to educational seminars you can view online or attend live by phone. These seminars may have been inspired by social media posts or may have clickable content when viewing the online version of the Kidney Citizen. Our goal is to leverage all forms of information sharing to best serve your needs.

In this issue, you will learn more about Fabry disease, a rare genetic disorder that can lead to kidney failure and will see how their support group, FSIG, grew by utilizing online communications. You will also read more about sexual health and dialysis, which corresponds with a previous education seminar that can be viewed online. We also included more information about how Dialysis Patient Citizens and the DPC Education Center are utilizing social media to improve advocacy efforts and the sharing of information on kidney disease research, treatments and clinical trials.

We hope you find this information beneficial as you navigate life as a kidney disease patient. Please consider liking and following us on Facebook to receive supplemental information in addition to this publication. ●

Sincerely



Nancy L. Scott  
DPC Education Center  
Board President



# The Dialysis PATIENTS Demonstration Act

By **Megan Beveridge**, Director of Congressional Relations, DPC

Bipartisan legislation was recently introduced by Reps. Jason Smith (R-MO), Earl Blumenauer (D-OR), Tony Cardenas (D-CA), Cathy McMorris Rodgers (R-WA) and Senators Todd Young, Bill Nelson (D-FL), Dean Heller (R-NV), and Michael Bennet (D-CO) to give dialysis patients access to coordinated care. Specifically, The Dialysis Patient Access to Integrated Care, Empowerment, Nephrologists and Treatment Demonstration (Dialysis PATIENTS Demonstration) Act would allow end stage renal disease (ESRD) patients access to coordinated care by establishing a 5-year demonstration program in which interdisciplinary teams provide holistic care to patients with ESRD. Coordinated care means that each health care provider serving a patient shares information with one another in a timely manner about the patient's health, treatments prescribed, and care delivered to him or her. Research has shown that coordinated care is helpful in improving the health of people with chronic conditions and in lowering their health care costs. Most people with ESRD also suffer from other chronic conditions like diabetes, high blood pressure, and cardiovascular disease, making their care more complicated. ESRD patients often need to see multiple health care providers and take many medications, particularly in the later stages of the disease. Care coordination reduces duplicative services, allows for the whole patient to be cared for and treated rather than just the specific disease, and can improve patients' overall health and quality of life.

Under this legislation, each participating team, or "organization" would be required to deliver all benefits under Medicare Parts A and B, as well as education and transition into transplantation, palliative care, and hospice care. Organizations would also be required to coordinate with Medicaid if necessary and provide additional services that would improve the health outcomes and reduce hospitalizations and readmissions. Some additional

services may include support for a healthy diet through a dietician, dental and vision care, and transportation services. These additional services could be life changing to many ESRD patients. When people think of kidney failure or transplantation, they often don't realize this, but directly related is a patient's oral health. For thousands of patients waiting for an organ transplant each year, maintaining good oral health, free of infection, is critical for successful organ transplantation and requires specialized dental care. Many patients will also need significant dental work done to simply qualify for a transplant and

H.R. 4143/S. 2065 would help those people with the access to the care they need.

Furthermore, having the ability to coordinate transportation services for these patients is extremely important. Approximately 90% of dialysis patients travel to a center three times a week for treatment, and because dialysis is a chronic outpatient treatment, patients are responsible for their own transportation. In fact, dialysis facilities are limited in directly helping patients with transportation, as providing transportation in their own private vehicles could be considered an inducement. This legislation would also change this and make it easier to transport these patients to and from treatment, ensuring far less missed treatments due to a lack of access to transportation.

Dialysis patients are a unique and complicated patient population. Access to coordinated, quality health care can be life changing for these patients. We here at DPC applaud these Members for working across party lines to produce this very important piece of legislation to improve not only the care for ESRD patients, but ultimately, also their quality of life. We encourage you to reach out to your Congressional Representatives and urge them to support the Dialysis PATIENTS Demonstration Act as well. ●

## Take Action Now

### Step 1

Visit [KidneyAction.org](http://KidneyAction.org)

### Step 2

Click "Support the Dialysis PATIENTS Act"

### Step 3

Enter your name and address and make any edits to the message and click send!

# Fabry Disease: When A Genetic Freight Train Crashes Into Your Life

By **Dawn Laney**, M.S., C.G.C.

The year was 2003, and I was preparing to step into an exam room and see a very ill, 30-year old man on hemodialysis. At this point, I was an experienced genetic counselor, but had worked mostly with pregnant women, newborns, and parents. I was not yet aware that walking into this room was a life-altering moment, one that would change the focus of my career and introduce me to the amazing patients, families, and stakeholders of one frustrating, sneaky, life-limiting genetic condition: Fabry disease.

Fabry disease is an inherited, progressive disease that is caused by genetic changes or mutations in the GLA gene that lead to reduced levels of the enzyme alpha-galactosidase A (AGA) in the body. Without enough AGA enzyme, specific molecules in the body that should be broken down instead build up in such a way that the blood vessels all over the body become narrowed. There are two main forms of Fabry disease: a severe “classic” form which impacts health beginning in childhood and a “non-classic” form that leads to early kidney

and heart disease but does not start in childhood.

Classic Fabry is like a freight train. The condition starts out slowly, making you wonder if the Fabry train is actually moving. In childhood, kids have stomach pain, overheat easily, and have invisible burning pain in their hands and feet particularly during fevers. They may have a few reddish-purple freckles in their belly button or in the “bathing trunk” region around the groin. Additionally, they may have a non-vision affecting “corneal whorl” that their eye doctor saw on a routine eye exam with the slit lamp. Other than genetic testing for Fabry disease, there is not an easy test that the pediatrician can do to explain the health issues, so kids are often told they are too anxious, having growing pains, or faking illness.

In their teens and twenties, the Fabry freight train picks up speed: the burning pain in the hands and feet is constant, pain crises are more frequent, stomach issues worsen, daily fatigue limits activities more noticeably, and the reddish-purple freckles in their belly button spread. In addition to

those issues, the first measurable medical hints appear: protein in the urine (proteinuria) and a slow heartbeat (bradycardia). In early adulthood, the Fabry freight train begins to come off the rails, roaring down the tracks and leading to kidney failure, serious heart issues including an enlarged heart and arrhythmias, severe and chronic fatigue, depression, anxiety, vertigo, hearing loss, neuropathy and pain in the hands and feet, fluid retention (edema), and eventually, strokes. All of these health issues create a laundry list of life-limiting problems that have patients moving from doctor to doctor seeking answers.

Back at the clinic, when I walked into that room in 2003, I met that exhausted, very ill man who was happy that he had been diagnosed with Fabry disease during a genetics consult by Emory physician, Dr. Paul Fenoff when he was in the hospital. Yes, you read that right, **THRILLED** to be diagnosed with this rushing freight train of a disease. Why? There were three reasons: First, he had an answer to all the pain and miserable health issues he had experienced. It was payback and “I told you so” to all the people who had told him it was all in his head and that his kidney and heart disease was from the drugs he took to dull the Fabry related pain. Second, there was an FDA approved treatment for Fabry disease, and although it was too late to save his kidneys, it hopefully could help stall the progression of Fabry disease in his body and help him have a better quality of life. Third, it explained the “family curse”, and maybe all that he had gone through would keep his kids, his mother, his brother, and his cousins from having to suffer without an answer for their medical issues. The earlier they began treatment, the more effective the therapy would be in slowing down the Fabry train.

The patient already knew about the therapy that had been approved by the FDA in April 2003 from his discussions with Dr. Fernhoff at his initial consult, but there were some key facts for us to review. Fabrazyme (agalsidase beta), manufactured by Sanofi-Genzyme, is an enzyme replacement therapy (ERT) designed to replace the enzyme that is lacking in people with Fabry disease. It is given through IV infusion every two weeks. Of course, that is not the only thing used to help treat the symptoms of Fabry disease. Patients with Fabry may also take medications to treat their neuropathic pain, decrease protein in their urine, reduce stroke risk, and address their anxiety and depression. Individuals with abnormal heart rhythms may also be treated with implanted pacemakers or implantable cardioverter defibrillators. For those with end stage renal disease, dialysis (hemodialysis and peritoneal dialysis) and kidney transplant are options. Of course, before kidney transplant, particularly from a family member, it is critically important to know that the donor does not **ALSO** have Fabry

## WHAT SHOULD YOU DO IF THIS SOUNDS LIKE YOU?

Did anything about the Fabry disease story sound like you, a family member, or the person getting dialysis next to you? We have included with this article an easy checklist that can help you think about Fabry disease. Take a second to run down the list.

1. Discuss with your healthcare provider your interest in getting tested for Fabry disease. Your doctor may be unfamiliar with Fabry disease, and that is ok. The best place for them to start researching Fabry disease is at [GeneReviews.org](http://www.gereviews.org).
2. Ask your eye doctor if you have corneal whorls. Not everyone with Fabry has them, but if you do it is an important clue.
3. Reach out to the Fabry Support and Information Group or the National Fabry Disease Foundation for help finding a Fabry expert in your area.
1. Talk to a genetic counselor. Find one in your area at: <http://www.aboutgeneticcounselors.com/>.

## DO SOME RESEARCH USING THE RESOURCES LISTED BELOW.

### Resources:

2. Fabry Support and Information Group 🌐: <http://www.fabry.org/>
3. National Fabry Disease Foundation 🌐: <https://www.fabrydisease.org/>
4. Fabry information on ThinkGenetic.com 🌐: <http://www.thinkgenetic.com>
5. Emory Fabry resources 🌐: <http://genetics.emory.edu/patient-care/lysosomal-storage-disease-center/resources.html>
6. GeneReviews Summary on Fabry disease 🌐: <https://www.ncbi.nlm.nih.gov/books/NBK1292/>
7. AAKP free family testing project 🌐: <http://genetics.emory.edu/patient-care/lysosomal-storage-disease-center/lab-testing.html>
8. Fabry disease summary sheet at my46.org 🌐: <https://www.my46.org/trait-document?trait=Fabry%20disease&parent=Genetic%20Syndromes&type=profile>
9. Fabry community- 🌐: <https://www.fabrycommunity.com/en/Patients/Education/Overview.aspx> Studies in Fabry disease
10. Search for Fabry disease on Clinicaltrials.gov 🌐: <https://clinicaltrials.gov/>



disease.

That one follow-up clinic visit in 2003 and the dizzying array of follow-up and treatment needs hooked me. I left that visit with as many questions whizzing through my head as the intake coordinators ask you at check-in when you visit the hospital. How can we help more people living with Fabry disease get diagnosed earlier? How many family members can realistically be expected to have Fabry disease after the first person is diagnosed? Does Fabry disease affect men differently than women? What other therapies could help people with Fabry disease live a better life? What could one genetic counselor do to help in this community?

Some of those answers became incredibly clear over the next few years. Fabry runs through families in an X-linked pattern. That means that every woman with Fabry disease has a 50% chance of passing Fabry disease to each of her children. It also means that every man with Fabry disease will pass the gene change causing Fabry disease to **ALL** of his daughters and none of his sons. On average when you find one person affected by Fabry disease, **FIVE** more of their family members will also be affected. In 2003, we had just fully realized that Fabry disease affects both men and women. Today, we know that some women with Fabry disease can be just as severely affected as men and most will have at least one life-impacting symptom of Fabry disease. This means that every woman with Fabry disease needs individualized care, monitoring, and treatment.

Getting tested for Fabry disease takes one simple blood

test. For men, testing usually starts with a measurement of alpha galactosidase A enzyme levels in blood followed by DNA testing designed to “spellcheck” the gene and look for mistakes that could cause Fabry disease. For women, the alpha galactosidase A enzyme test will miss many women affected by the disease, and so the DNA test looking at the GLA gene must be done to confirm Fabry disease.

Once the gene change is known in a family, then other family members can be tested for the GLA mutation in the family. In fact, there is a program that provides testing for free, and can be done using a saliva or blood sample.

Additionally, now there are studies investigating everything from the impact of Fabry disease on babies diagnosed through newborn screening to gene therapy treatments. In 2017, there are at least four therapeutic approaches being tested through clinical trials, each trying to effectively treat Fabry disease. Once these clinical trials are completed, the FDA will review the evidence and decide which ones will be approved for use in the United States.

As you can see there are plenty of questions that can keep Fabry experts very busy. I have learned that one genetic counselor can help solve a few mysteries of Fabry disease through listening to key things that most impact the people and family members living with the condition and designing ways to systematically study those questions. ●

# An Introduction to Fabry Disease

By **Jack Johnson**, Executive Director Fabry Support & Information Group

Fabry disease is a rare lysosomal storage disease that is inherited, caused by a mutation on the X chromosome in a section of genetic code that produces the alpha-galactosidase A enzyme or A-gal for short. Lysosomes are the recycling centers of the cell and this is where A-gal goes to do its work of breaking down certain fatty glycolipid materials, specifically one with a big long name referred to as GL3 or sometimes called GB3. If you do not have sufficient functioning A-gal, GL3 builds up filling the lysosome and causing cellular damage.

Fabry is a disease that runs in my family. I was seeing Robert Desnick M.D., Ph.D., one of the leading researchers on Fabry disease and he encouraged me to start a support group for people with Fabry. With very little direction on how to accomplish this, my family and I set out to do just that. Starting in 1996, as one of those true kitchen table groups, we formed the Fab-



ry Support & Information Group (FSIG). We thought we could help by spreading information about the disease, and so we started by producing newsletters.

We began with fewer than 20 names so that first newsletter did not have very wide distribution. But after creating a website, that quickly changed. Today, we have members

all across the United States and more than 40 foreign countries around the world.

As the organization grew, it went from something we could manage on weekends and evenings to a full-time commitment. As a result, I found myself

transitioning from my previous work life to a new one for FSIG. As the membership and needs of the Fabry patient community grew, the programs and services that were needed grew as well. Unlike so many rare diseases, treatments for Fabry were being developed for clinical trials needed participants. With keen interest from the medical



and pharmaceutical communities, FSIG received donations and grants to meet the needs of our growing organization.

In the beginning, we naively thought the need for a Fabry organization would diminish after a treatment became available. We were told the opposite would be true, and, after an Enzyme Replacement Therapy (ERT) received FDA approval in 2003, we found that to be the case.

The Fabry patient community is comprised of a very diverse group of people. Fabry is proving to be a complicated disease that is equally diverse in its impact on people. Fortunately, interest from the medical community in wanting to understand the disease more fully did not lessen once a treatment became available. Instead, interest increased, and efforts to develop improved next-generation treatments have intensified in recent years. Whether a cure can someday be developed is not known, but hope is still alive.

**Fabry Support & Information Group (FSIG)**

108 NE 2nd St  
P.O. Box 510  
Concordia, MO 64020  
660-463-1355 or toll free at 866-30-Fabry  
(866-303-2279)  
[Info@Fabry.org](mailto:Info@Fabry.org)

## When to Consider Fabry Disease as a Diagnosis\*

Anyone who has a family member with Fabry disease and/or corneal whorls on eye exam should be tested for Fabry disease. In addition to those cases, anyone with at least two things below should consider testing for Fabry disease.

1. Family history of Fabry Disease
2. Decreased or no sweating in the heat or with exercise (anhidrosis or hypohidrosis)
3. Reddish-purple skin rash in the bathing trunk area (angiokeratomas)
4. Personal and/or family history of kidney failure
5. Personal or family history of “burning” or “hot” pain in the hands and feet, particularly during fevers (acroparesthesias)
6. Personal or family history of problems with overheating when exercising or having burning pain in the cold.
7. Corneal verticillata (“whorls”) that usually do not effect vision, found by eye doctors on eye exam with a slit lamp

\* Modified from J Genet Couns. 2013 Oct; 22(5): 555-564. Published online 2013 Jul 17. doi: 10.1007/s10897-013-9613-3





# Walking in Their Shoes: A Conversation About Living With Fabry Disease

an interview with [Lisa Bacon](#)

Often the best way to learn about living with a specific health issue is to go straight to the people who understand it best: those living with it. In this spirit, we sat down with Lisa Bacon to learn more about Fabry disease and its impact on her family.

**When did you learn that Fabry disease was present in your family?** We learned about Fabry disease in our family over ten years ago. My dad was diagnosed through his kidney doctor. We had long known something was wrong with his health, but it took a kidney biopsy to solve that mystery.

**Since that day, how many people in your family have been**

**diagnosed with Fabry disease?** Seven people, including me and my dad.

**When you first learned that you had Fabry disease, were you surprised?** No, because we were told that if your father has it, then all the girls will definitely have it. Fabry disease is genetic, which means it runs in families. The changed gene that causes Fabry disease is on the X-chromosome, which means the gene will pass down, if the father has it, to all his daughters. When a mother has Fabry disease, there is a 50% chance for each of her offspring to inherit the gene.

**What were the first symptoms of Fabry that you recognized in hindsight in your father?**

Growing up my dad would always have to stop at every rest stop to use the restroom. He also would have extreme fatigue. I noticed his purple angiokeratomas (lesions on the capillaries) at an early age, but never thought anything about it.

**Have you ever had difficulties getting medical care for your Fabry disease because of the incorrect and out-of-date belief that women were “just carriers” not affected by Fabry**

**disease?** Not really because I am comfortable advocating for myself. However, my primary doctor doesn't seem to comprehend it all.

**What is it like to be in the “sandwich” generation, with a parent and a child being affected by Fabry disease?** Watching my dad's health get so bad at an early age definitely affected my son's outlook on his own life. We all try to live a healthy, active life and try to be involved in learning more about Fabry so that one day there will be a cure.

**How did you decide when to start the FDA approved enzyme replacement therapy for Fabry that involves getting the medication through an IV twice a month?** My son's test results left no doubt that he needed to start enzyme replacement therapy (ERT) at an early age. My goal is to get him the best care. For myself, I am working closely with my doctors, and when my results start showing



symptoms, I will consider treatment as well.

**What do you wish that you knew 15 years ago about Fabry disease?** I think God's timing for our dad to be diagnosed was in His perfect time. Although my dad suffers from not being diagnosed earlier, my son received his diagnosis to receive ERT at a great time.

**What do you think is important for people living on dialysis to know about Fabry disease?** You can still live an active life being on dialysis. My dad still travels and functions fairly well.

**Any other words of wisdom**

**about living with Fabry disease?** For a long time, I questioned every health concern as if it might be Fabry-related because there are no definite answers for a woman living with this disease. But now I understand that there are many things that may never be understood, and I'm okay with that. I try to eat healthy and stay active and if things do come up that I am concerned about, I seek the necessary answers and don't worry about it being related.

**Any other words of wisdom about being a mother of a child living with Fabry disease?** I treat my son as I do my other two children. He wouldn't want it any other way. It is hard thinking about your children having to live on this drug for the rest of their lives, but when you look around at many other children who have it far worse, we are thankful that he lives a fairly normal life that is only interrupted for a few hours every other week. ●

# Clinical Research 101: Participating in a Trial

Written by **Kurt Mussina**, MBA, Frenova Renal Research

## What Is Clinical Research?

Long before a medicine is approved by the U.S. Food and Drug Administration and put on the market, it undergoes rigorous testing to ensure it is safe and effective — a process that can take many years. Testing new and/or already approved medicines in people is what we call clinical research. Although there are many different types of clinical trials, I am focusing here on the clinical development and approval process for drugs and devices, in particular.

Clinical research is vital to finding ways to improve quality of life and to finding cures for diseases. It gives researchers all kinds of information they need to make good decisions. For example, it tells the researcher if the medicine works well in pill form or if it possibly works better as an injection. It helps the researchers determine the size of the dose and how much should be given at a time and how often. It tells the researchers how effective the medicine is. And much more. Without clinical research, there simply would be no new medicines. Without clinical research, we can forget about finding better treatments for kidney disease. That is the simple truth.

## What Does Clinical Research Have to Do With You?

**Join us** for an education webinar on **December 7 at 2pm ET** entitled **Clinical Research 101: Participating in a Trial** visit [www.dpcedcenter.org](http://www.dpcedcenter.org) for more information

Unfortunately, most people don't know much about clinical research or about studies that are available. That makes clinical research difficult, because we need many people willing to step up and participate in clinical research — all kinds of people.

Sometimes medicines are tested in healthy volunteers. For example, a cold medicine may be tested in people who are generally healthy. But often, patients with a particular disease or condition are required. After all, it's hard to test a new medicine for a particular cancer unless you can test it on people who have that cancer.

Similarly, if researchers want to test how well a treatment for kidney disease works, then they are going to need to test it in people with kidney disease. Sometimes, too, volunteers



with kidney disease may be needed even if the treatment isn't specifically targeted to kidney disease. For example, researchers may want to learn how well a medicine for heart disease works for people who have kidney disease.

This is where you come in.

### What Are Clinical Trials?

When researchers are ready to test a medicine in people, they organize a clinical trial. There are more than 254,000 of these clinical trials for all types of diseases underway now around the world, and more than 44,000 of these studies are actively looking for people to participate in them. (This is information from [ClinicalTrials.gov](http://ClinicalTrials.gov), a federal website that tracks all the trials.) It's not just medicines that need to be tested. Medical devices — such as the stents surgeons place in heart patients or the monitors that diabetes patients use to test their blood — need to be tested in clinical trials, too. Some trials even study surgical procedures to help doctors determine what procedure will help their patients the most.

Perhaps you heard the word “phase” used in connection with clinical trials. There are four different phases of clinical trials. You might want to think of them as elimination rounds. If the medicine or medical device fails in any phase, then the trial ends right there. Here's generally how it works:

**Phase I** — The medicine is typically tested on 15 to 30 healthy volunteers just to make sure that it is safe and doesn't cause any bad side effects.

**Phase II** — The medicine is tested in a larger group of people, maybe 100 to 200. In this phase, researchers are trying to determine how effective the medicine is. Does it actually help treat the condition, and does it help treat the condition better than other medicines that are already available?

**Phase III** — Researchers test the medicine on many more people, perhaps 1,000 or more. They are looking to make sure that there aren't any major side effects in some people. They are also hoping to confirm what they found out in Phase II about how well the medicine worked.

If the first three phases — or elimination rounds — go well, then the company developing the medicine or medical device can ask the U.S. Food and Drug Administration (FDA) for approval to start selling it. If the FDA approves, then it goes on the market. That takes us to the final phase.

**Phase IV** — After the medicine is already on the market, and presumably being used by people around the country, some drug companies may still have an obligation to make sure its medicine is safe. So, the company will conduct tests in an even larger group of people to make sure the medicine is safe and not causing any additional side effects.

### Why Participate? What Do You Get Out of It?

Many of us have heard of someone who is really sick and is participating in a clinical trial. Maybe this person hasn't been helped by any of the medicines available today and hopes to get help from a new medicine not yet on the market. Certainly, this is an excellent reason to participate in a trial.

But researchers need more than these people. There simply aren't enough people willing to volunteer. They need healthy people to volunteer for trials, and they need patients with specific health conditions to participate.

You may decide you want to participate to learn more about kidney disease and its treatments. Or, you may want to participate to see if the medicine can improve your day-to-day life. Or, you may just want to have a role in helping others who are living with kidney disease or people who will get kidney disease in the future. Whatever your reason, we hope that you will consider joining a clinical trial.

### How Can You Get Involved?

If you think you might be interested in clinical research or you just want to know more, your first step is to talk to your doctor. Let him or her know of your interest. You can also explore the many online resources available that provide additional information about clinical trials, such as the [Center for Information & Study on Clinical Research Participation](http://CenterforInformation&StudyonClinicalResearchParticipation), or [ClinicalTrials.gov](http://ClinicalTrials.gov), where you can search for all kinds of available trials.

Once you decide on a potential study, you can contact the study team, who will lead you through the process. Keep in mind that you are in no way committed to a clinical trial yet. This is just your chance to find out more.

You will meet with a nurse or doctor on the team who will probably ask for some information about your medical history. This information helps the study team determine if you meet the requirements for study participation and if you can safely join the research study.

The nurse or doctor then will meet with you to tell you all the details about the study and what will be required of you. If you want to bring a family member or a friend with you, that is perfectly fine. You will learn what drug company is behind the study and what the medicine is supposed to do. You will learn what the medicine’s potential benefits and risks are, and you will learn what will be required of you. Most importantly, you will have an opportunity to ask all your questions. In fact, the study team is required by law to make sure that all your questions are answered, so don’t be afraid to ask any question! Here’s a partial list of questions you should ask. Again, be sure to add questions of your own:

- What is the main purpose of the study?
- Does the study involve a placebo or a treatment that is already on the market?
- How long will the trial last?
- What am I required to do?
- Will I need to travel to a clinic? Where? How often? Will I be required to stay overnight?
- Will I need to have my blood drawn? How often? When?
- What are the potential benefits of the study drug?
- What are the potential risks and side effects?
- Will I be reimbursed for travel and other expenses?
- Do I need health insurance to participate in the trial?
- When and how will the results of the clinical trial be provided to me?

Once you feel you have all the information

you need, then you can decide if you want to participate. If you want to talk it over more with your family first, then you can do that. If you decide you want to participate, then you will be asked to sign an informed consent form, which basically acknowledges that you have been given all the information you want and that you willingly agree to participate.

**Here’s something very important for you to know: By law, you can quit the study at any time — and you don’t even have to give a reason. Your decision to participate is your choice and remains your choice at all times.**

At some point, you likely will be asked to undergo some initial procedures, such as getting your height, weight, temperature and blood pressure measured or perhaps giving a blood or urine sample. There might be a physical exam. This is because the doctor in charge of the clinical trial needs to know about your health and medical history to ensure the study is safe for you. The doctor’s most important job by law is to make sure all volunteers in the study remain safe.



So, some people — because of their medical history or the medications they are taking or for some other reason — will not be allowed to participate in the study. The clinical trial’s doctor will let you know whether or not you are accepted. If you are accepted, then you’ll be given instructions, such as a time when you need to report to the clinic.

**Should You Be Concerned About Your Safety?**

Absolutely. But you also should know that there are many others looking out for your safety, too. As mentioned earlier, the most important job of the doctor in charge of the clinical trial is to keep you safe. If you experience an unexpected side effect, that doctor will make sure you are taken care of. So, be sure to always let the study team know how you are feeling and always ask any questions you have.

Secondly, long before you or any of the other study volunteers can get involved in a study, a group of independent doctors and researchers — people who have absolutely no connection with the study at all — is required by law to take an in-depth look at all the plans for the study. They also look at all the research that has already occurred. Not until they say everything looks okay, can the study begin. Plus, they also keep tabs on the study as it goes along.

And, never forget, if you ever want to drop out of the study, you are allowed to do so.

**What if Clinical Trials Aren’t for You?**

Volunteering for a clinical trial is always your choice. If you decide to volunteer for a trial, you should take pride in knowing

that you are helping to find better treatments to help people lead healthier lives. But, if you choose not to volunteer, that is fine too. Maybe this isn’t a convenient time for you. Or, maybe you feel this just doesn’t feel right to you. That’s okay. We understand. We hope that you will spread the word and teach others about the importance of clinical research. Perhaps by telling others, you will find that some of your family members or friends will want to volunteer for other studies.

When we go to the pharmacy to pick up a prescription or when we have to go for a treatment in a clinic or a hospital, we seldom think about how that medicine came to be. We never think about the thousands of people who volunteered to take that medicine as an experiment before it was ever approved. Thanks to the volunteers who participate in clinical research, we are being helped every day and we have hope that doctors can find better treatments, better medicine, to improve our lives in the future. ●



**HUMAN  
ORGAN**  
FOR TRANSPLANT

# The Truth about Transplants: How to Cope After Surgery

By **Hannah Calkins**, writer and editor for the American Psychological Association

*This resource was developed jointly by the American Psychological Association (APA) and Dialysis Patient Citizens Education Center as part of a partnership to educate dialysis patients and their families on the psychological and emotional aspects of managing kidney disease.*

Ideally, receiving a kidney transplant is a totally transformative experience for patients. A successful transplant can mean an end to the agonizing uncertainty of the waitlist, relief from dialysis and its attendant complications, and—hopefully—renewed energy, health and a return to “normal” life.

But even people whose transplants go exactly as planned can experience anxiety, depression and difficult emotions related to their transplant. They may find it harder than expected to adhere to new medication routines, or have transportation issues that affect their ability to keep medical appointments. Their relationships may be strained. They may have trouble returning to their prior work, or adjusting to new professional roles. Some may struggle with ongoing mental health issues or substance use, or be in financial distress as a result of their medical costs.

You probably already know that these problems can affect your quality of life and the function of your new kidney. But

with the help of your transplant team, there are steps you can take to protect your physical and emotional health.

**Be prepared to adjust your expectations.** Staying positive is important, but be careful about pinning your hopes on a dramatic, immediate transformation. You should be prepared for the possibility of complications, says Jody L. Jones, Ph.D., a transplant psychologist with the University of Iowa Hospitals and Clinics.

“When you’re feeling hopeful, and when all you want is for dialysis to end, it can be hard to absorb that you may not have a smooth course,” Jones says. “But I try to help patients stay present in the moment, and focus on taking care of themselves as best as they can.”

Even if you don’t experience medical complications or have any trouble adhering to post-transplant routines, there may be other challenges. For example, it may take longer than you planned to return to work or other activities—and you may

not be able to return to them at all. Your transplant team can help you manage expectations and set realistic goals.

**Find opportunities for growth.** This can be an opportunity to learn about yourself, especially if you need to identify new pathways to earning a living.

“Use this time to look at what you can do with your life. You can move forward,” Jones says. “It may be in a direction you weren’t anticipating, but that’s okay. Feel inspired by the challenge, not stricken by it.”

That might mean going back to school, learning a trade, or getting some other kind of training. “This may be a time to try something new, to focus and learn,” Jones says.

**Let go of guilt and shame.** These feelings can come up at many points along the timeline of your transplant experience, says Audrey A. Krause, Ph.D., a transplant psychologist with the Indiana University School of Medicine and IU Health.

For one, it’s common for patients receiving kidneys from deceased donors to worry that someone had to die in order for them to get better. They may feel bad about being grateful for another’s loss.

Krause helps patients reframe those feelings, suggesting that they think of it this way: “A grieving family has lost a loved one, and you are bringing them additional meaning to that loss.”

Patients who receive kidneys from living donors can wrestle with feelings of guilt, too, especially if the donor is a relative. Underlying dynamics—such as those between parents and children—can be a source of stress, though Krause says that usually the relationships between recipients and donors are strengthened through the transplant process.

Feelings of guilt and shame are also common for people

who need another transplant, especially if they weren’t compliant with post-transplant medical regimens. People in that situation may feel like they made a mistake and don’t “deserve” another kidney.

Krause meets these feelings with compassion, and it’s likely that your team will, too. A mental health professional can help you navigate those feelings, as well as help you overcome emotional, psychological, and practical barriers to success.

“You’re only human. No one expects you to be more than that,” Krause says.

**Rely on your transplant team, and be open with them about your struggles.** Remember that your team is there to support you and wants you to succeed.

Fundamentally, it’s their job to educate you about maintaining your health, set realistic expectations, and help you get support systems in place. They can help you if you’re struggling with anxiety, depression or other mental health issues.

They also may be able to help if you have problems with your insurance coverage or finances. “If you can’t afford your medications, you may be embarrassed and feel like you can’t share that,” Jones says. “But it’s not your fault, and please don’t be ashamed. Often, we can connect you with medical assistance programs or tap into other sources of support.” The key, though, is to communicate.

“In order for us to help, you have to let us know if you’re struggling,” Krause says. “We can problem-solve with you and help you get over all kinds of stumbling blocks, so please speak up.” ●

# My Gift of Life Journey

By **Paul Rakoski**

I was diagnosed with Fabry Disease in February 2007 after undergoing a kidney biopsy to determine the cause of my poor kidney function. Up until that point, nobody in my family knew of the disease and its effects. Shortly thereafter, my mother, sister, niece and nephew were diagnosed. We choose to not let it define who we are but rather deal with it as best as we can.

Within 1 year, I was seeing my nephrologist at Massachusetts General Hospital (MGH) every two months. In the summer of 2008, he had me meet with the dialysis staff and mentioned that I was going to need a kidney transplant sooner rather than later. My first thought was "How do I go about asking someone if they would be willing to donate a kidney to me?"

Friends and family knew I was sick and I kept them up to date via periodic emails (no Facebook for me at that point in time...). I sent an email with the latest news and included that I was beginning to look for a kidney donor. In that email, I included the name and contact information for the Donor Coordinator at MGH. I was fortunate to have a couple of people tested and even more fortunate to have a match...a college friend! On February 24, 2009, I was given the gift of a

second chance at life!

I've always been active, playing sports as a child and adult. After the transplant, I saw a poster in the transplant clinic for the U.S. Transplant Games (now known as the Transplant Games of America). In 2014, I decided to participate when the Transplant Games of America in Houston, TX (not the best place for Fabry patients in July!). I participated in Golf, Track & Field, and Swimming and was fortunate enough to win 2 Bronze Medals (Swimming and Track & Field). The Games are an amazing 5-6 days that celebrate life and are something I would recommend for anyone who has donated or received an organ.

Two years later, I participated again, this time in Cleveland





where I won a silver medal in Team Golf. During these events, I spoke with people about the World Transplant Games and what they were all about. I was told that they're just as amazing, and that they're very competitive.

So, this year, with the support of my entire family, I, along with my wife, headed to Malaga, Spain to participate in the World Transplant Games, where over 2,000 competitors from 50+ Nations came together to compete and raise awareness for organ donation. Leading up to the games, I made it a point to train as much as possible. My choices of sports were golf, pairs kayak, and the cricket-ball throw. I golfed at least once a week (a lot for me!), borrowed a friend's kayak, and went to the local high school to try to strengthen my throwing shoulder. Every business trip included the golf clubs so that I could play at least 9 holes after work. My first event was individual golf, and I won a silver medal in my age bracket.

Next up was pairs kayaking where my teammate, Amy (from Texas), and I won silver medals in the 200M sprint and 1000M race. A medal in cricket-ball throw was not in the cards, but I finished top 5 in my age group so for that, I was happy.

The bottom line is this: I **TRY** to live every day to its fullest and do the best I can with the gift I have been given. Not every day is easy, trust me. Infusion days lead to being tired, the GI issues know no bounds, and there are days I do not want to move off the couch. I try to remind myself that there is someone, somewhere, with a struggle far more difficult than mine.

Here is my advice: Believe in yourself; try to remain positive when things get difficult; and advocate for yourself and others.

On a side note, try to attend the Charles Kleinschmidt Fabry Camp at Victory Junction in Randelmann, North Carolina if you have not. If you have already checked off that box as a participant, think about volunteering. It is a blast! My wife and I do not have children, so I have made the trip the last 3 years as a volunteer. It

## Key questions to ask your doctor if you have been diagnosed with Fabry disease

1. What are some health issues I need to watch for now that I am diagnosed with Fabry disease?
2. Can you help organize testing for my family members who might have Fabry disease?
3. What is the plan for watching me for future Fabry health issues?
4. What other specialist doctors should I be seeing routinely?
5. What are my treatment options for Fabry disease and individual health problems I am having?
6. Can you tell me about any studies I might qualify for at this time?
7. Can you help me find a Fabry Center of Excellence and a genetic counselor to work with you to manage my disease?

is very rewarding to spend three days seeing smiling faces and forgetting about the struggles of dealing day to day with Fabry. Unfortunately, I will not be there this year but plan on being there in 2018! ●

# Using Social Media for Advocacy

By **Kristy Lukaszewski**, Director of Policy and Communications

What was once a platform for connecting with friends, social media has become a vessel for policy change. After a contentious Presidential election, people are looking for new ways to engage with policymakers to make sure their voices are heard. The Women's March on Washington was rooted in a call-to-action on Facebook. The creation of one Facebook event page in Hawaii snowballed into a 500,000-person march in Washington, D.C. and several international marches for advocates to voice their concerns about policy proposals of the new administration. Facebook reports users spend an average of 50 minutes on their sites a day, and patient advocacy

organizations can use this to their advantage. Dialysis Patient Citizens (DPC) is utilizing social media to mobilize individuals to take action on behalf of dialysis patients across the country. After the release of a discriminatory ruling by the Centers for Medicare and Medicaid Services (CMS), DPC launched an online petition to the incoming administration encouraging them to overturn this rule. By using Facebook's audience targeting, we reached over 38,000 individuals who had an interest in kidney disease and educated them about this discriminatory rule. Over 24,000 of these patients, healthcare professionals, and family members signed the petition. Not only were we able to cultivate signatures on the





in 2016. It is also important to note, those 968 emails were for one campaign only. After acquiring over 5,000 new Facebook likes, we began to cultivate these individuals into active members.

Through a series of carefully crafted posts to “ease” individuals into what our organization does, we were able to convert 318 of those individuals into active advocates by simply sending a message to Congress to introduce themselves. Imagine what the turnout will be when we need to launch an issue-based campaign!

By scheduling and promoting daily posts about our organization, current calls to action, and news in the kidney community, we are reaching around 45,000 people a week. Maintaining an active social media presence will lead to increased action when issues arise that need immediate action.

petition, but we grew our total Facebook audience by 142%. So, how has this affected our advocacy efforts? Since January 1, patient advocates have sent 968 emails to legislators as opposed to 243 messages during the same period. While Facebook continues to explore its role in politics and information sharing, it is already a great tool to mobilize individuals into active policy advocates. Have you liked us on Facebook yet? Visit [facebook.com/patientcitizens](https://facebook.com/patientcitizens) for daily news and updates! ●

# When You Have Lost That Loving Feeling: Sex and Intimacy on Dialysis

By **Erich Ditschman**

“Well, hello, Mr. Ditschman. How is your sex life?”

This is one greeting I have never heard in my dialysis clinic. Okay, well maybe by Michael in the waiting room. And yes, I did blush. But, I never heard this once from my doctor, nurse, dietitian or social worker. In my 17-years on dialysis, sex has not been that big of a concern for my medical team, certainly not as big as keeping me alive.

If you check out your dialysis clinic’s website, you will probably find a link near the bottom of the page to a “Sexuality on Chronic Kidney Disease” page. Here you might be reminded that you have been too busy trying to adjust to your new normal of dialysis, while trying to take care of your family, work and finances, to think twice about sex, let alone once about intimacy.

If this sounds familiar, but if you  
are not

quite sure of the difference, here is a quick refresher. In a recent DPC Education Center webinar, David Spero described sex as physical contact that brings pleasure, excitement and connection. He stresses that sex is not limited to intercourse nor the use of genitals at all. He describes intimacy as contact (not necessarily physical) that brings closeness, safety and love. See accompanying box for a list of sex and intimacy benefits.



For me, I could not focus on any of that until I found a part of myself that I could recognize. I needed some light to pierce the forest of fear in which I was lost—a glimmer of clarity from which I could convince myself that I could do this dialysis. In the beginning hope is transient, like the sun peeking through a dark cloudy day. Just as the sun brings relief and a smile, hope makes us persevere.

Like many, I initially crashed into dialysis. One day, I was working, finishing a graduate degree, and enjoying our one-year-old son with my wife. Then three months later, a central line was placed in my chest. Soon after, once many of the toxins had cleared, my social worker brought a man with a fistula to my chair. My vanity said no way. My body would never look normal again.

It was not until five months later, after the kidney I named “Annie,” donated by my wife, failed, and a fistula was placed, and memories of my once prominent libido flickered in my dreams. But with three times a week treatment, I still felt consumed with dialysis. Any energy I had was devoted to my family. As I settled into a routine, I felt stronger. On some days, I even rode my bike to the dialysis center a mile away.

Still, it did not occur to me to bring up the subject of sex and intimacy to my team. I was not quite there. Perhaps one of the reasons my team had not brought it up was because the topic has not been well studied. In his recent review of literature related to male sexual dysfunction and kidney disease, Matthew Edey points out, “Historically, this cause of considerable morbidity has been under-reported and under-recognized.” A similar observation can be made for female sexual dysfunction

and kidney disease. This is confirmed with a simple Google search. See the accompanying box for potential causes of CKD Sex Problems.

Eventually, the following things occurred which finally brought the desire for sex back into my life. I stopped acting sickly. I took control of my treatments. And, I became the leader of my medical team. It was

### Health benefits of sex:

helps with sleep  
relieves pain  
is a mild form of exercise  
improves system function  
lowers blood pressure

### Life benefits:

improves self-defined quality of life  
raises self-esteem  
improves relationships and intimacy  
motivates self-management  
provides emotional support/comfort

Source: David Spero, Sex and Intimacy with CKD, The Dialysis Patients Citizens (DPC) Education Center (<http://www.dpcedcenter.org/sex-and-intimacy-ckd-recording-now-available>), 2017.

### Causes of CKD Sex Problems

Vascular (blood flow vessels)  
Endocrine (hormones)  
Neurologic (nerve damage)  
Pharmacologic (medicine)  
Anemia (blood volume)  
Hyperparathyroidism (hormones)  
Psychologic (depression)

Edey, M. M., Male Sexual Dysfunction and Chronic Kidney Disease in Medicine (<http://journal.frontiersin.org/article/10.3389/fmed.2017.00032/full>), March 22 2017, pp.1-32.

not until I experienced the stability of regular in-center treatments that I began to grasp the reality that dialysis was my gift of life. I came to an understanding that additional kidney transplants may or may not be in my future, and that I had to stop being a patient waiting for a cure. I had to start living my life fully each day, while riding the crazy roller coaster that is dialysis.

My wife and I will be celebrating our 30-year wedding anniversary in January. She recently reminded me that from her standpoint intimacy was hard because most of the time I was unable to share closeness, not sex, but just being emotionally close. She noticed that when I was not dialyzed well, or anemic, that I was unable to be present. She also had concerns with touching my fistula and whether I might have a heart attack if we did have sex.

During in-center treatments, I started researching home hemodialysis using a 70-lbs. portable dialysis machine. I found a center about an hour away from home where it was offered, and my nephrologist agreed to re-credential so I could try it. The hardest part of training for me was learning to stick the dialysis needles in my fistula. But that was my ticket home. I am generally a fainter, but I thought about my son and our then one-year-old daughter, and how I needed to be there for them. So, I pushed the needle in and somehow, unlike the many techs and nurses at the clinic, I poked it perfectly. Sure, there was pain. A few years after, when I replaced my fistula with a graft and could no longer use the tunnel technique, I experienced pain when I poked where there was no scar tissue. I occasionally do still. But, this pain reminds me that I am in control of my treatments and I am no longer a patient, rath-

er just a guy who has a glorified toilet at his bedside, my dialysis machine. I give dialysis about as much thought as when I used to lift the lid and pee—and, of course, then shut the lid. The switch to more frequent dialysis at home was a game changer for my libido. I really had not realized what I had lost until I started daily dialysis. I even wrote the President of the dialysis company and told him that his machine was better than Viagra. My wife noticed the difference too, reminding me that by being better dialyzed, I felt better and had more energy.

I used this energy to pay more attention to her. I had the strength to give her back massages and to take on more responsibility at home. For the past number of years, as our roles have changed, I have taken care of the grocery shopping, and try to make sure we have a tasty meal when she comes home from work. I recently took her on a surprise vacation for her fiftieth birthday. These are the things that lead to intimacy in our relationship. And, with intimacy comes physical connection.

I no longer wait for my team to approach me about sex and intimacy. As the leader of my medical team, I started the conversation. When my physical ability could not keep up with my desire, I asked my nephrologist about Viagra. After attending a dialysis patient conference, in clinic I asked my social worker about vacuum pumps and implants and whether or not they are covered by Medicare. Both Medicare and private insurance companies cover these treatments. And, yes, I had to get over the fact that many on my team are women. I mean what was I going to do, ask my wife to ask for me?

My dialysis team still does not ask me about my sex life, but I give them an answer anyway. It is getting better all the time. ●

# The Creations of a **Chef** with CKD

By **John Vito**

My name is John Vito and I was a restaurant owner and chef for over 20 years. I was diagnosed with End Stage Renal Disease (ESRD) in 2011 and immediately put on dialysis. For the 5 1/2 years I spent on the machine, I researched all I

could about my newly diagnosed illness. I broke down the treatment options, limitations and what I could do to be engaged in my own care.

The first thing I learned was that doing dialysis and running my two restaurants was not going to be a possibility for me. I had to step out of that life and begin to focus on my own health. It quickly became apparent that there were three aspects to dealing with my ESRD: 1. Medication, 2. Dialysis, and 3. Diet and exercise. The only item I had any control over was the third, and I wanted to learn as much as I could as it had been my profession for all those years.

I began asking my doctors and my registered dietician lots of questions, and while I had complete confidence in their knowledge about their specific areas of expertise, there was something missing. Neither of them had sat in the chair, nor were they cooks. This is where I thought I could



participate and maybe help others.

I started researching the food side to the answers they provided and applied them to my interest and understanding of creating in the kitchen. I deconstructed recipes and ingredi-

ents and started to find out ways to make them healthier for my condition. The result has been my project **Cooking for your Kidneys** ([cookingforyourkidneys.com](http://cookingforyourkidneys.com)) where I created a pilot video series of cooking shows. I provide recipes, videos, and information about food and how it affects patients with CKD.

The recipes and videos combine information from a nutritionist and my knowledge of cooking to create tasteful and healthy meals. We discuss topics such as sodium, phosphorus and protein while I cook a delicious meal that you also can prepare at home.

Earlier this year I received a transplant and now that my energy level has significantly increased, I hope to continue to add to this website. My goal is to provide patients and caregivers 24- hour access to the one aspect of treatment we can control: our "diet." ●



1012 14th Street NW Suite 1475  
Washington, DC 2005

NON PROFIT ORG  
US POSTAGE  
PAID  
SEATTLE, WA  
PERMIT NO 2191



**DPC Online Store NOW OPEN!**

Visit

**[www.kidneymall.org](http://www.kidneymall.org)**

**to get your DPC gear for the Holidays!**

