

2023 KIDNEY PATIENT SYMPOSIUM



NATIONAL KIDNEY
FOUNDATION®

JOIN US!

VIRTUAL

APRIL 24–APRIL 28

6:00pm–7:00pm ET
via Zoom Webinar

LINKS:

Monday..... [kidney.zoom.us/s/83558539543](https://kidney.zoom.us/j/83558539543)

Tuesday [kidney.zoom.us/s/85961933611](https://kidney.zoom.us/j/85961933611)

Wednesday [kidney.zoom.us/s/86710013404](https://kidney.zoom.us/j/86710013404)

Thursday [kidney.zoom.us/s/82654784467](https://kidney.zoom.us/j/82654784467)

Friday..... [kidney.zoom.us/s/84551978778](https://kidney.zoom.us/j/84551978778)

IN-PERSON

SUNDAY, APRIL 30

1:00pm–4:00pm ET
Holiday Inn South
Independence, OH 44131

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NATIONAL KIDNEY
FOUNDATION

A PATIENT & CAREGIVER VIRTUAL EVENT

SCHEDULE OF EVENTS

PROGRAM AGENDA

VIRTUAL BREAKOUT SESSION AGENDA FOR APRIL 24–28

April 24, 6:00pm-7:00pm Kidney Transplant 101

Kristen Graf

Zoom Webinar Link Access: kidney.zoom.us/s/83558539543

April 25, 6:00pm-7:00pm Understanding Clinical Trials

Dr. Andrew Lazar

Zoom Webinar Link Access: kidney.zoom.us/s/85961933611

April 26, 6:00pm-7:00pm NKF and Kidney Advocacy

Matthew Fitting & Lauren Drew

Zoom Webinar Link Access: kidney.zoom.us/s/86710013404

April 27, 6:00pm-7:00pm CKD 101 IN SPANISH

Dr. Laura Provenzano

Zoom Webinar Link Access: kidney.zoom.us/s/82654784467

April 28, 6:00pm-7:00pm ABC's of CKD in Kids

Dr. Amy Bobrowski

Zoom Webinar Link Access: kidney.zoom.us/s/84551978778

IN-PERSON BREAKOUT SESSION AGENDA FOR APRIL 30

1:00pm WELCOME

1:10pm–2:00pm FIRST ALL-GROUP SESSION

Topic: *Basics of Eating with CKD*

Presenter: Meredith Miller, RD, CSP, LD and Kristin Bame, MS, RDN, LD

2:00pm–2:10pm BREAK

2:10pm–3:00pm BREAKOUT TOPICS (*Participants select 1 of 3 options*)

1. Gout Bingo – Conner Mertens
2. Disparities in the Kidney Community – Drs. Jill Green, PhD and Rima Kang, MD
3. Mental Health and CKD – Andrew Linder, M.A.Ed, LPCC-S, and Emily Linder, M.Ed., LPCC-S

3:00pm–3:10pm BREAK

3:10pm–4:00pm SECOND ALL-GROUP SESSION

Topic: *Kidney Patient & Caregiver Panel*

Presenter: Resa, Steph, Edgar, Roberta, Brian and Tamara

Panel Moderated by: Dr. Rupesh Raina

4:00pm EVENT END

This event would not have been possible without our Medical Advisory Board and Patient Symposium Committee Members!

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The National Kidney Foundation is revolutionizing the fight to save lives by eliminating preventable kidney disease, accelerating innovation for the dignity of the patient experience, and dismantling structural inequities in kidney care, dialysis and transplantation. By supporting the National Kidney Foundation, you directly influence and positively impact the lives of those at risk for kidney disease, those living with chronic kidney disease, and those who care for and about them.

KIDNEY DISEASE IS A MAJOR PUBLIC HEALTH ISSUE

- 1 in 3 American adults are at risk for kidney disease.
- 1 in 7 American adults has kidney disease — and most don't know it
- High blood pressure and diabetes are the two leading causes of kidney disease.
- Of 118,000 Americans on the waiting list for a lifesaving organ transplant, more than 96,000 need a kidney.
- Fewer than 25,000 people receive one each year.
- There are 500,000 Americans receiving dialysis.
- There are 200,000 transplant patients.

KIDNEY DISEASE LOCALLY

The Northern Ohio territory is comprised of 32 counties with a population base of 5.2 million people. When the national statistics are applied to our local population, the need for patient support and community education programs is undeniable. In Northern Ohio:

- An estimated 1.73 million people are at-risk of kidney disease.
- An estimated 742,000 people have kidney disease and 90% of them are undiagnosed.

A MESSAGE FROM OUR EXECUTIVE DIRECTOR, ANNA TZINIS



NKF has taken a bold stand in addressing the healthcare disparities that plague our communities of color and delay the diagnosis and treatment of kidney disease. While our efforts are ever-growing, here are a few highlights of the past several years:

In December 2021, we reached one of our most important goals when the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act was signed into law. It will change the lives of thousands of patients receiving Medicare, who can now afford transplantation because their immunosuppressive drugs will be covered for the life of their transplant.

In March of 2022, we passed House Bill 188 in the state of Ohio, which prohibits life, disability, and long-term care insurers from unfairly discriminating against living organ donors in the offering, issuance, premium, or conditions of such a policy. This bill allows more people to step forward to become living organ donors.

In 2022, we launched a joint Task Force with the American Society of Nephrology to examine the role of race in diagnosing and treating kidney disease and developed a race-free eGFR calculator. This changes how we diagnose kidney disease going forward.

In October 2023, we will host the first Ohio state-wide forum called Ending Disparities in Kidney Disease Leadership Summit, which will create an impact strategy to develop and advance equitable solutions to improve CKD testing and diagnosis in primary care.

Collectively, we made an incredible impact on the medical community, care partners, and patients. Thank you to all those who have contributed to this important work; I personally invite anyone who has not joined us already to join our NKF network of committee members, board members, advocates and volunteers.

With gratitude and in service,

Anna Tzinis

LEADERSHIP



Our Virtual Patient Symposium is led by event Chairman, **RUPESH RAINA, MD**. Dr. Raina is an Adult-Pediatric Kidney Disease/Hypertension Nephrologist at Akron Children's Hospital, Akron Nephrology Associates at Akron General Medical Center, Cleveland Clinic Foundation at Medina and MetroHealth Department of Nephrology. He is also an Associate Professor at NEOMED Medical University and Council Member for Faculty of Internal Medicine Council at NEOMED, Research Director at AGMC, Associate Program Director of Internal Medicine, and works in partnership with Americare Kidney Institute. Dr. Raina is the Pediatric Education Chair for the International Society of Nephrology. Additionally, Dr. Raina serves on both the local National Kidney Foundation Board of Advisors and the Medical Advisory Board.



The National Kidney Foundation, Serving Northern Ohio Medical Advisory Board is chaired by **APARNA PADIYAR, MD** who is the Assistant Professor of Medicine at Case Western Reserve University School of Medicine and Director of the Transplant Nephrology Fellowship Program at University Hospitals Cleveland Medical Center. Dr. Padiyar received her bachelors, medical degrees, and internal medicine training at the University of Michigan-Ann Arbor. She completed fellowships in both nephrology and hypertension and transplant nephrology at University Hospitals Cleveland Medical Center. She has cared for over 2,200 transplant recipients through the life of their allograft, from the time of transplant to the time to return to dialysis or re-transplant or to their passing with a functioning graft.

SESSION SPEAKER



KRISTEN GRAF BSN, RN, CCTC currently works as a Pre Kidney and Pancreas Transplant Coordinator at University Hospitals Cleveland Medical Center. She has been a nurse for 25 years and she has worked in transplant for over 20 years. She has been a Certified Clinical Transplant Coordinator since 2012. In 2017 she was a honoree of the Winners of the Faces of Care Award from Cleveland Magazine. In 2020 she was awarded The Kidney Foundation of Ohio Marilyn Bartucci Excellence in Nephrology Nursing Practice award. She is grateful to be a part of the 8th Annual Patient Symposium. As a living donor kidney recipient in 1996, she shares with Patient Symposium participants and attendees her passion for kidney transplant.

SESSION SPEAKERS



DR. ANDREW LAZAR is a nephrologist in Cleveland, Ohio. He has a degree in biomedical engineering from Boston University and spent the first part of his career as an engineer in the automotive industry. His expertise was that of software applications for the design and testing of automotive components. He obtained his medical degree at Wayne State University in Detroit, Michigan. He studied internal medicine at the University of Virginia and completed a Nephrology fellowship at Case Western Reserve University in Cleveland, Ohio. Dr. Lazar founded Cleveland Kidney Disease Associates and is currently the chief of Nephrology at Ahuja Medical Center in Cleveland, Ohio. He has founded and operated in-center hemodialysis units but has a particular interest in home dialysis therapies.



MATTHEW FITTING provides strategic direction and oversees implementations for all of NKF's advocacy activities. Prior to joining NKF, he was an Advocacy and Engagement Specialist with the American Nurses Association (ANA), where he led the organization's efforts to deepen nurses' involvement in the political process. Prior to ANA, Matthew led public affairs campaigns to engage and activate the American Heart Association's volunteer community as federal grassroots advocacy manager. Prior to his time at the AHA, Matthew was a senior associate with the Dewey Square Group's grassroots practice, guiding issue advocacy campaigns for clients that included national non-profits, trade associations, corporations, and political campaigns.



STEPHANIE LIEBERT is a Living Kidney Donor since August 2019 when she donated for her brother-in-law through a paired donation. She lives in Brooklyn, Ohio with her husband, Greg, and their three sons (Jared 17, Tyler 15 and Blake 11). She is a physical therapist who works full time at Cleveland Clinic as the Team Lead of Strategic Initiatives for the Cleveland Clinic Rehabilitation and Sports Therapy Department. She spends the majority of her time actively being involved with her sons activities which include attending St. Ignatius Marching Band Performances, St. Ignatius Bowling matches, St. Thomas More Basketball games and Competitive Gymnastics with her youngest who competes with the Above the Barre Men's Gymnastics team.

SESSION SPEAKERS



LAUREN DREW is the Director of Congressional Relations for the National Kidney Foundation, where she promotes kidney health appropriations and legislation on Capitol Hill. Before joining NKF in 2020, she was the Senior Manager for Grassroots Advocacy at the National Hospice and Palliative Care Organization, and before that spent time in several DC-based advocacy organizations, campaigns, and Capitol Hill offices. A graduate of Villanova School of Law and the Elliot School of International Affairs at The George Washington University, she is originally from New Jersey but currently resides with her partner and dog in NE Washington, DC.



DR. AMY BOBROWSKI received her medical degree from Washington University in St. Louis in 2001, and subsequently completed a pediatric residency and pediatric nephrology fellowship through Northwestern University's Feinberg School of Medicine. Dr. Bobrowski was the Medical Director of Kidney Transplantation at the Ann & Robert H. Lurie Children's Hospital of Chicago until the summer of 2020, at which time she transitioned to the Cleveland Clinic to assume the positions of Center Head for Pediatric Nephrology and Medical Director of Pediatric Kidney Transplantation at Cleveland Clinic Children's.



EDGAR L. CLOUD SR. is 59 years old and was diagnosed with end stage renal failure and started dialysis treatment on October 19, 2019. He opted against at home dialysis treatments and instead became a patient at Fresenius Medical Care receiving dialysis treatments 4 hours a day 3 days a week. After going through the process and being approved, he was added to the transplant waiting list with the Cleveland Clinic and the Veterans Affairs Hospital. After 3 years, on June 23rd 2022, he received that call for a kidney transplant and he is here today as a proud kidney transplant recipient.



ROBERTA WERVEY is a 1994 graduate of the University of Mount Union where she earned her B.A. in Sociology. She went on to have a successful career as a case manager working in both alternative sentencing programs and mental health outreach programs in Cuya County. Ms. Wervey was part of the original pilot project of the CIP (Children of Incarcerated Parents). She has been a speaker on patient panel for the American Association of Kidney Patients in St. Louis, discussing various different modes of dialysis treatment. In Ms. Wervey's spare time she sings and plays percussion at church. She is also part of her medical response team. Ms. Wervey received a kidney transplant 12 years ago at The Ohio State Medical Center.

SESSION SPEAKERS



KRISTIN BAME MS, RDN, LD completed her bachelor's degree in nutrition at the University of Dayton and her master's degree, also in nutrition, at Central Michigan University. She worked as a renal dietitian for 15 years in home and hemodialysis with both pediatric and adult patients. Although currently employed non-clinically, her passion for renal nutrition continues. She loves keeping up with current nutrition research and being a part of the renal community through volunteer work. In her spare time, her favorite things to do are play with her three kids and attend weekly Sunday dinners with her family.



MERIDETH MILLER is a registered and licensed dietitian nutritionist in Ohio. She received her BS in Human Ecology from The Ohio State University. She has been a Board Certified Specialist in Pediatrics for the past 10+ years. She has been practicing pediatric nutrition at the Cleveland Clinic for 20 years and 17 of those years have been in nephrology. Merideth specializes in all areas of nephrology (inpatient and outpatient) from hypertension and kidney stones to CKD, ESRD (hemodialysis and peritoneal dialysis) and transplant nutrition. In addition, she is the lead dietitian at Cleveland Clinic Children's Hospital for Rehabilitation having worked in the world of pediatric rehab for 19 years. She is the dietitian for the pediatric chronic pain program and the Cerebral Palsy clinic.



CONNER MERTENS is a patient advocate and community outreach manager at the Global Healthy Living Foundation. He graduated from Willamette University in 2017 with a bachelor's degree in Political Science. Conner got his start in advocacy and activism during his time in undergrad, when in 2014, he became the first active college football player to come out publicly. After which, Conner has sat on multiple boards for local and national LGBTQ+ organizations, and founded his own non-profit to support homeless LGBTQ youth. Conner discovered his passion for advocacy while working as a public speaker on issues like suicide prevention, anti-bullying, and LGBTQ issues.



RESA CLANSY is 67 years old. She is a Minister and a mother of four, a grandmother of ten and a great grandmother of four. She was previously employed with Cleveland EMS as a paramedic. Resa was diagnosed with Systemic Lupus in 2002. After several hospitalizations she was given a diagnosis of Chronic Kidney Disease and started to work with a kidney nurse, which helped her kidneys to continue to work for 12 years. After her kidneys shut down she did peritoneal dialysis for 5 years and had to go on in-center hemodialysis for about for about 6 months and was then called for a kidney transplant surgery. She thankfully received a kidney on December 20, 2020 and it was the start of a new journey. Her hobbies include camping, crocheting and classical music.

SESSION SPEAKERS



JILL A. GREEN, PhD is a Clinical & Scientific Director at Otsuka Pharmaceutical Development and Commercialization, Inc (OPDC). Dr. Green received her PhD in biomedical sciences from The Ohio State University, with a specialization in biochemical and molecular basis of disease. She went on to hold various pre-clinical and clinical trial management positions at The James Comprehensive Cancer Center, before joining the Otsuka Field Medical Affairs team in 2018. Jill is a proud living kidney donor and a member of the PKD Foundation's Central Ohio chapter, where she has been active in fundraising and advocacy efforts for over 14 years.



RIMA KANG, MD is an Assistant Professor of Clinical Medicine, within the Division of Nephrology at The Ohio State University, in Columbus, Ohio. Dr. Kang received her medical degree from Northeast Ohio Medical University and completed her residency in Internal Medicine at the University of Cincinnati Medical Center. Dr. Kang then went on to complete a distinguished fellowship in Nephrology at The Ohio State University Wexner Medical Center. Upon joining faculty at Ohio State, Dr. Kang has become the lead nephrologist in cystic kidney disease care and was instrumental in developing a specialty clinic at Ohio State with an emphasis in ADPKD and CKD care.



EMILY LINDER, M.Ed., LPCC-S is the clinical manager at IBH Addiction Recovery and is also a counselor/co-owner of Calibrations Counseling & Consultation. She graduated from the University of Akron in 2011 with her bachelors in psychology and went on to obtain a master of arts degree in clinical psychology from Cleveland State University in 2013. After spending a year working as part of a research team, she went back and obtained a master of education degree in clinical mental health counseling from University of Akron in 2017. She specializes in working with individuals with anxiety, depression, addictions, ADHD, and struggles with life transitions. Emily became a caregiver to her husband, Andrew, when he developed stage 5 kidney failure in 2018 and donated her left kidney to him in 2019.



ANDREW LINDER M.A.Ed, LPCC-S is a Licensed Professional Clinical Counselor for the state of Ohio. Andrew graduated from Massachusetts College of Pharmacy and Health Sciences in 2012 with a BS degree focusing on Health Psychology. He then attended the University of Akron where he received his M.A.Ed with a focus on Clinical Mental Health Counseling. Andrew has experience providing counseling services to adolescents/young adult, adults, and the geriatric population. Specific issues he has experience in include but are not limited to: Anxiety, Depression, Substance Abuse, Chronic Illness, Grief, End of Life Issues, ADHD, PTSD, Life Adjustments, and other. Besides counseling, Andrew has become an advocate and volunteer for the kidney community, providing support where he can.



BRIAN AND TAMARA ROZEK have been married for 16 years. Thanks to a living kidney donor they will have many more. Polycystic Kidney Disease runs in Brian's family. The disease ran its course quicker than expected. Brian needed a kidney transplant. It was an uncertain time for both Tamara and Brian. However, they were determined to find a living donor. Tamara created a website and used social media for the "big ask". A year had passed and Brian was just a few weeks shy of starting dialysis, when he got the call. A Coast Guard colleague he served with was a match. Lori passed the testing with flying colors and drove in from Michigan to save her shipmate. They are both going strong four years after the transplant.

SESSION SPEAKER



DR. LAURA FERREIRA PROVENZANO is a nephrologist at the Department of Kidney Medicine, Glickman Urological and Kidney Institute; and the Medical Director of the Ohio Home Dialysis Unit at the Cleveland Clinic. She is a Clinical Assistant Professor of Medicine at the Lerner College of Medicine of Case Western Reserve University. She completed her medical school training at the University of Buenos Aires, Argentina. Most recently, she joined the combined Rheumatology-Nephrology Lupus Clinic. She is an author of peer reviewed publications, book chapters, several abstracts and posters that have been presented at National and International Nephrology Meetings. She is also a member of the American Society of Nephrology, the National Kidney Foundation and the International Society of Peritoneal Dialysis. Her clinical interests include home dialysis, glomerulonephritis with a primary focus on lupus nephritis, as well as inpatient nephrology.



Medication Adherence in CKD

ARE YOU TAKING YOUR MEDICATIONS? *Michelle Hawkins, MD*

As a survivor of Chronic Kidney Disease (CKD) and a double kidney transplant recipient, I can speak from experience the need to take your medications faithfully. If you want to combat CKD, you need to take your prescribed medications.

One of the most important questions I ask my patients as a healthcare provider is are you taking your medications every day. Medication adherence is simply taking your medications correctly as prescribed by your doctor. This involves getting the prescription filled, remembering to take on time and understanding the directions.

As a patient, I was tested in following this procedure as I was diagnosis with CKD. I moved from stage 2 (mild CKD) taking several medications to stage 5 (End Stage Kidney Failure) taking over ten prescriptions daily. The challenge for me was comprehending why I had to take these medications, which have possible numerous side effects. Additionally, I had to make sure it is covered under my insurance plan at a cost that was financially feasible to me. Fitting into my schedule was a dilemma, as some of my medications needed to be taken without food and some with food. I got a pill dispenser to organize my medicines. Furthermore, I set an alarm to help remind me to take at certain times. I was told to keep my medications in a dry cool place. Formerly, I was taking a lot of complementary medications, which had to be evaluated for possible side effects with my immunosuppressive medications. At each doctor visit, my list was reviewed by both the nurse and physician to see if I was compliant. The social worker would come in to see if I need assistance with my medication coverage. After my transplant, the transplant coordinator was my go to person for getting my medications refilled. She provided me with a new pill dispenser when I left the hospital with a long list of medications. This nurse spent a lot of time with me while in hospital, explaining my medications and side effects. The transplant nurse also set me up with a specialty pharmacy to get my medications sent to my home address.

Let us get motivated at taking care of our kidneys to produce the best optimal health. Poor adherence to your medications must be changed by talking with your provider about what barriers are keeping you from benefiting the most of your medications. I strongly encourage you to know your medications.

As a champion for CKD, I want to inspire you to look within yourself to see what you can do to improve your medication adherence. Ask yourself:

1. Am I taking all my medications?
2. Why did I decide to stop my medications without my physician advisement?
3. Am I skipping doses or taking at the incorrect time?
4. What are the consequences if I do not take my medications?
5. When I travel, do I carry enough extra doses for an extended stay?
6. Am I checking for possible side effects and alerting my physician of the ill effects?



Dining Out with CKD

Kristin Bame, MS, RDN, LD

Having chronic kidney disease (CKD) should not limit the fun of dining out. Prepare before you leave by looking at the menu and nutrition information online. Ensure other meals eaten that day are low in potassium, phosphorus, protein, or fluid if you are monitoring these nutrients. Don't forget your binders if they have been prescribed and take them during your meal.

At the restaurant, ask questions about the menu and request substitutions if needed. Order a la carte to individualize your meal as appropriate. Also, consider the following:

- **To limit sodium**
 - Ask for food to be prepared without salt.
 - Ask for sauces and gravies on the side.
 - Limit ketchup, mustard, steak sauce, hot sauce, etc.
 - Ask for salty food on the side (i.e., hold the pickles).
- **Beverages count as fluid.**
 - Avoid refills if you are limiting fluid.
 - Avoid colas, orange or tomato juice, milkshakes, and beer. They contain potassium and/or phosphorus.
 - Choose lemon-lime soda, water, coffee, or wine if your doctor has stated it is OK to consume alcohol.
- **Caution with soups. They often are high in sodium and count as fluid.**

To avoid overeating, cut your dish in half when it arrives. Put half in a to go bag and enjoy the other half. Or share a meal with friends.

Different types of cuisine are very enjoyable. Consider the following depending on where you dine:

American Food– Limit lunch meat. Hold the cheese. Avoid potatoes, fries, chips. Choose rice or noodles (i.e., macaroni salad). Grilled chicken, pork, fish, or steak are good choices for main dishes.

Chinese Food – Request MSG on the side. Do not add soy, teriyaki, or fish sauces. Choose egg rolls, white rice, Dim Sum. Chicken, beef, or pork stir fry should be a good choice. Request it with low potassium vegetables such as peppers, onions, carrots, water chestnuts, snow peas, cabbage, or pineapple if monitoring potassium.

Soul food – Limit ham, bacon, sausage, and organ meats such as chitterlings. Greens, spinach, yams, sweet potatoes, chickpeas, and dried beans are high in potassium, so use caution if necessary. Choose chicken, corn, green beans, okra, corn bread and peach cobbler.

Italian Food – Avoid tomato sauce if you are watching potassium. Limit cheese. Flavor with red pepper flakes. Choose oil-based sauces. Italian bread dipped in oil and vinegar is a good choice.

Mexican Food – Avoid chips and salsa. Minimize cheese intake. If you are limiting potassium, use caution with guacamole, salsa, and beans. Fajitas with peppers and onions likely are a good choice. Flavor with sour cream.

Amounts of recommended phosphorus, potassium, fluid, and protein vary by stage of CKD and from person to person. In general, if you have CKD, it is usually a good idea to limit sodium. Talk with your doctor or dietitian about what restrictions you may need and remember them when you eat out. Enjoy!!

The websites below are good sources for more information:

kidney.org/sites/default/files/docs/diningout.pdf

health.ucdavis.edu/food-nutrition/pdf/Kidney%20Disease%20-%20Renal%20Dining%20Out%20Guide.pdf

freseniuskidneycare.com/recipes-and-nutrition/dialysis-diet-planning/eating-out

davita.com/diet-nutrition/articles/advice/eating-out-on-the-dialysis-diet



CAROLYN LANDIS, PhD



CHRISTINA NGUYEN, MD



JULIA SMITH-PAINE, PhD

Psychological Characteristics of Pediatric Kidney Transplant Recipients

Most children and teens have healthy psychological functioning throughout their kidney transplant process. However, having had a kidney transplant in childhood relates to a higher risk of certain mental health conditions, including depression (17-36%), anxiety (20-36%), attention (22.5%), and post-traumatic stress disorders (Amatya, Monnin, & Christofferson, 2020). The following factors can be protective or helpful for pediatric kidney transplant recipients:

- Parents do not have these same psychological disorders,
- Parents have had the opportunity for more education,
- The family structure and environment are positive,
- Child/teen misses less school
- There are fewer rejection episodes and physical or medication side effects.

Chronic kidney disease can also affect children’s development. This includes their thinking and learning skills. Thinking skills often improve following kidney transplant, but these children are still at higher risk for concerns. Most children who have received

a kidney transplant have overall intellectual skills (IQ) in the average range but still show lower IQ scores compared to healthy children. Children who have a kidney transplant are also at higher risk for having learning difficulties in school.

For now, it is important to pay attention to your child’s psychological functioning, development, and learning. Speak with their doctor if you or your child’s teachers have concerns. A pediatric psychologist*, neuropsychologist**, or other behavioral health professional as part of the kidney transplant care team can help too. They can offer screenings, behavioral interventions such as therapy, and expert advice for your child to receive extra supports in school.

Take-home points:

- Ask your child’s kidney transplant team about the availability of psychological screening both pre- and post-transplantation.
- If children/teens are found to have psychological conditions that might affect their school success (e.g., attentional problems), even

if these are not learning problems, they may qualify for support through a 504 Plan.

- If diagnosed with thinking or learning differences, children/adolescents might be eligible for an individualized education program (IEP) for special school services.

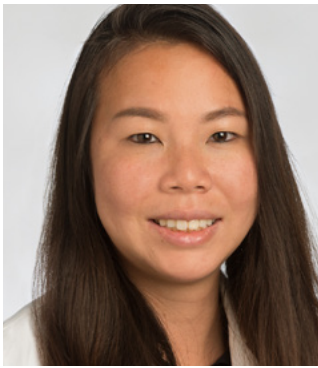
Footnotes:

**Psychologists who specialize in the well-being of children and adolescents with medical conditions are “pediatric psychologists.”*

***Psychologists who specialize in evaluations to measure behavioral and cognitive changes from medical conditions are neuropsychologists.*

References: Amatya, K, Monnin, K, Steinberg Christofferson, E. Psychological functioning and psychosocial issues in pediatric kidney transplant recipients. *Pediatr Transplant.* 2021; 25:e13842. doi.org/10.1111/petr.13842

Fernandez HE, Foster BJ. Long-Term Care of the Pediatric Kidney Transplant Recipient. *Clin J Am Soc Nephrol.* 2022 Feb;17(2):296-304. doi: 10.2215/CJN.16891020. Epub 2021 May 12. PMID: 33980614; PMCID: PMC8823932.



BOONYANUTH MATUROSTRAKUL, MD



ANNE HUML, MD

Kidney Transplantation from Donors with Hepatitis C

Boonyanuth Maturostrakul, MD and Anne Huml, MD

According to the United Network for Organ Sharing, there are approximately 93,000 patients on the waiting list for kidney transplant in the United States. Most patients will wait about 4 years until they receive a kidney transplant (1). Since 2018, kidney transplants from deceased donors who have a history of hepatitis C infection have been safely transplanted to recipients who do not have hepatitis C (2). Hepatitis C is an infectious disease that is caused by a virus that can affect the liver. About 3% of all kidney transplants done in the United States in 2022 were from kidney donors who tested positive for hepatitis C infection (3).

Patients with kidney disease who are waiting for a kidney transplant and are interested in hearing about receiving a kidney from hepatitis C positive donors are educated extensively regarding the process. They will meet with a liver doctor (hepatologist) for education and to determine if there

is any medical reason that would prevent them from receiving a kidney transplant from a hepatitis C positive donor. Patients will then determine whether to give permission, or consent, for organ offers from hepatitis C positive donors. Patients considering accepting a kidney transplant from a hepatitis C positive donor can discuss the pros and cons with their kidney doctor or transplant team. In some cases, getting a kidney from a donor with hepatitis C can occur faster than waiting for a kidney donor without hepatitis C.

After receiving kidney transplant from a hepatitis C positive donor, transplant recipients will then receive an oral medication (called, glecaprevir/pibretasvir or sofosbuvir/velpatasvir) either at the time of the transplant surgery or once their blood tests turn positive for hepatitis C virus. Recipients will take these medicines for 8-12 weeks to complete treatment. Recipients of hepatitis C kidney

transplants are closely monitored for hepatitis C by checking blood to ensure that they are cured from the virus. Once treatment is completed, the recipient is monitored frequently afterwards to ensure that they continue to be free of the virus.


Almost 100% of kidney transplant recipients who contracted hepatitis C from hepatitis C positive donor kidneys are successfully cured from hepatitis C after receiving oral antiviral treatment without any clinically significant liver dysfunction (2). These oral medications are highly effective and well tolerated without many side effects.

Patients whom receive hepatitis C positive kidney are found to continue to have very good kidney function months to years after kidney transplantation (2). The transplant community is optimistic that hepatitis C is no longer a barrier for patients who are waiting for life-saving organs.

References:

transplantliving.org/kidney/the-kidney-transplant-waitlist

Sise, Meghan E., et al. Multicenter Study to Transplant Hepatitis C-Infected Kidneys (MYTHIC): An Open-Label Study of Combined Glecaprevir and Pibrentasvir to Treat Recipients of Transplanted Kidneys from Deceased Donors with Hepatitis C Virus Infection. *JASN* 31(11):p 2678-2687, November 2020. | DOI: 10.1681/ASN.2020050686 optn.transplant.hrsa.gov/data/view-data-reports/national-data/



If you have Polycystic Kidney Disease you may qualify for a clinical study

www.PKDstudy.com



FALCON
a study in polycystic kidney disease

WHAT IS CLINICAL RESEARCH?

Clinical research is medical research that involves people like you. People volunteer to participate in investigations that ultimately uncover better ways to treat, prevent, diagnose, and understand human disease. Clinical research includes trials that test new treatments and therapies as well as long-term natural history studies, which provide valuable information about how disease and health change over time. There may be both benefits and risks associated with clinical research trials. These should be discussed in detail with your physician or the clinical study team.

ABOUT THE STUDY

FALCON is a Phase 3 clinical study evaluating the effectiveness and safety of bardoxolone methyl (an oral investigational drug) in patients with Autosomal Dominant Polycystic Kidney Disease (ADPKD).

WHO CAN JOIN THE STUDY?

YOU MAY BE ELIGIBLE FOR THIS STUDY IF YOU:

- Are 12 to 70 years of age
- Have been diagnosed with ADPKD

Other eligibility criteria will apply.

For more information or to see if you qualify, contact:

Joanna Figueroa
Patient Navigator
joanna.figueroa@reatapharma.com
(469) 442-4754



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US-BARD-2300003 02/2023



Non-Prescription Medications and Kidney Disease

Nishighanda Pradhan, MD

Many “over-the-counter” medications are freely available without a medical prescription. These include medications used to treat common ailments such as upper respiratory infections, pain, constipation as well as nutritional supplements and herbal products. Though often helpful in treating mild symptoms, these medications can pose unique dangers for patients with kidney disease. I am going to review some of the common over the counter medicines and the risks they could pose to patients with kidney disease.

-Anti-inflammatory medicines like ibuprofen, naproxen, indomethacin, celecoxib, sulindac : Commonly used to treat inflammation and pain, these medications can raise blood pressure, cause potassium levels to increase, sometimes to dangerous levels, dangerously lower serum sodium level and also cause acute damage to kidneys worsening their function further. **Long term, regular use of these medications can cause chronic kidney disease.**

-Pain medications like acetaminophen: Though generally considered safe for patients with kidney disease, high doses (4 grams per day of acetaminophen daily by mouth) taken regularly may raise the blood pressure. Such high doses may also cause injury to the liver.

-Acid reflux medicines like omeprazole, pantoprazole: These can sometimes cause an allergic reaction in the kidneys causing kidney injury. Long term use may also cause chronic kidney disease and low magnesium levels which can be dangerous to the heart.

-Antacids such as calcium carbonate: Excessive intake of calcium containing antacids can cause high calcium levels causing kidney damage. Additionally, aluminium or magnesium present in some antacids is toxic to patients with kidney disease.

-Laxatives such as milk of magnesium and polyethylene glycol: Laxatives may cause disturbances in the levels of various electrolytes in the body. Additionally, the magnesium in magnesium containing laxatives may lead to dangerously high magnesium levels.

-Enemas such as phosphate containing enemas (ex. Fleet TM): These can lead to dangerously high phosphorus levels in patients with advanced kidney disease or on dialysis.

-Decongestants like Sudafed: Raise blood pressure and worsen blood pressure control.

-Herbal medications and nutritional supplements: Many herbal medications can cause side effects such as raising the blood pressure (yohimbe, licorice) or even cause kidney damage (Chinese herbal weight loss teas). Sometimes they may be contaminated with dangerous substances like lead, cadmium, arsenic which are toxic. They may also interfere with levels of other medications in the body, particularly those used to suppress the immune system following a kidney transplant.

-Special risks for patients with kidney transplants: Kidney transplant recipients need to take powerful anti-rejection medicines to suppress the immune system. These medicines are processed by the liver and are very sensitive to disturbances in their levels due to interactions with many medicines and supplements such as St. John Wort, Echinacea, blue cohosh grapefruit etc. which can cause loss of the transplanted kidney.

How can you protect yourself from unintended side effects of over the counter medications?

-Always inform your health care provider about all the medications you are taking including over the counter and herbal medications and supplements.

-Avoid use of herbal medications and nutritional supplements as these may contain harmful contaminants such as heavy metals.

-Always read labels to find the name of the active ingredient

-Use minimum possible doses of over the counter medicines for as short a duration as possible.

-Do not take any medications or supplements without discussing with your transplant team if you have received a kidney transplant.

For further information:

[kidney.org/atoz/content/acid-reflux-and-proton-pump-inhibitors](https://www.kidney.org/atoz/content/acid-reflux-and-proton-pump-inhibitors)

[kidney.org/atoz/content/herbalsupp](https://www.kidney.org/atoz/content/herbalsupp)

[kidney.org/atoz/content/painmeds_analgesics](https://www.kidney.org/atoz/content/painmeds_analgesics)



Living Kidney Donation and Donor Resources

Wilda Kore, RN

Living kidney donation allows an individual to make a life altering gift to another in need. The process of becoming a living donor can be challenging and time-consuming. Donor candidates may be required to make lifestyle adjustments to move through the process. Employed candidates may need to make arrangements with their employer for time away, evaluation appointments and the recovery period. Appropriate planning prior to evaluation and donation is essential for the donor.

The evaluation, the surgery, and follow ups are all covered by the recipient's insurance. What resources are available to help offset donation-related expenses not covered by insurance? The expenses associated with travel, lodging, and lost wages can often discourage eligible candidates from donation altogether. How can we decrease the financial barriers and as a result increase access to living kidney donation?

There are various programs available to assist donors with donation-related expenses. The National Living Donor Assistance Center (NLDAC) assists eligible donors with costs of transportation, lost wages, and

dependent care expenses through reimbursement. Eligibility is determined by income and need. Potential donors should work with a transplant staff member to submit an application for review.

Patient assistance programs are another source of funding available to eligible kidney donors. Organizations such as the American Transplant Foundation help cover living expenses for donors facing financial difficulties. Some transplant centers may have internal assistance programs that they offer to their donors. Cleveland Clinic currently offers patient assistance to donors who qualify. Potential donors should speak with transplant staff for additional information.

Kidney donor assistance is also available through the National Kidney Registry (NKR). The NKR is a network of transplant centers working together to increase the number of living donor transplants. Donors who donate through the NKR may be eligible for financial assistance through the Donor Shield program.

Living kidney donation is an amazing gift that requires time and commitment from the donor. Donors elect to give the gift of life with no expectations in return. Removing financial barriers can help to make kidney donation possible and accessible to more potential donors, and will in turn make a dramatic difference for our kidney failure patients.

For more information regarding financial assistance

American Transplant Foundation

americantransplantfoundation.org/programs/pap/

National Living Donor Assistance Center (NLDAC)

livingdonorassistance.org

National Kidney Registry-Donor Shield

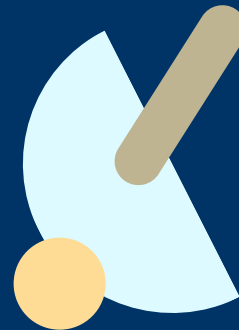
donor-shield.org/kidney-donors/



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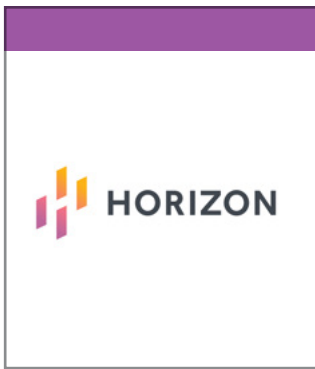
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Rethinking Gout and the Connection to CKD

Horizon Therapeutics

While hypertension and diabetes are well accepted as causes of chronic kidney disease (CKD), a range of studies have indicated that gout and elevated serum uric acid levels can serve as an independent risk factor for the development and progression of CKD as well. Taking a deeper look at this provides the opportunity to better understand gout and uric acid's connection with kidney health.

Gout should be considered a disease of the kidneys

There's a strong connection between gout and kidney disease because we primarily rely on the kidneys to remove uric acid from the body. When the tiny needle-like gout crystals form, they can build up almost anywhere in your body – not just in your bones and joints, but also in the walls of blood vessels and many of the body's internal organs – even in the kidneys.

People with kidney disease may be more likely to develop gout. In fact, research shows that nearly 1 in 4 U.S. adults with moderate-to-severe CKD have gout, and that the prevalence of gout is more than ten times greater for those who have undergone a kidney transplant than the general population. Importantly, analyses have shown that higher serum uric acid levels are associated with higher rates of transplant-related complications as well as higher rates of transplant failure.

Addressing the underlying cause of gout

Some medicines relieve the painful inflammatory symptoms of a gout attack, while others aim at lowering the concentration of uric acid to treat the source of gout crystals to prevent gout attacks from happening in the first place.

When you have both gout and CKD, treating gout can be difficult because some medicines for acute and chronic gout need to be dose-adjusted or avoided altogether based on your reduced kidney function. But as serious and difficult gout can be for patients with chronic kidney disease, the good news is that treatments are available for even the worst cases. If you are under the care of a nephrologist for your CKD, make sure that specialist is involved in your gout care plan. Through appropriate diet and medications, lowering your uric acid can dramatically improve your health and quality of life and make gout a completely curable disease.

Resources

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Spring Cleaning Your CKD Pantry

Merideth Miller, RD, CSP, LD

We spring clean our houses: clean the windows and get rid of clutter, but what about your pantry? What foods do you think of when you think of spring? Fresh fruits and vegetables? Lighter foods like salad and grilled chicken or fish? Let's clean out those pantries and add foods that are healthier. Your food choices will depend on what stage of kidney disease you have, but good nutrition is important for everyone. Speak with your doctor and/or dietitian for your specific needs.

Fresh foods are the best choice. Be aware of foods that contain a lot of salt such as pre-made soups, boxed meals (macaroni and cheese and skillet meals), cured or processed meats, canned vegetables and salt based seasonings (garlic salt, onion salt). Instead, choose low sodium broth, fresh pasta or rice, fresh or frozen fruits and vegetables, fresh meats and fresh or dried herbs.

Depending on your restrictions, you may have to limit the amount and types of fresh fruits and vegetables you eat. It is important to include fruits and vegetables in your day for vitamins and minerals your body needs to stay healthy and work well. Use the below list to choose foods that are low or medium potassium foods.

Use fresh pasta or rice to make your own soups or side dishes. Fresh or dried herbs such as garlic, onion, basil, black pepper and oregano can add flavor to low salt recipes. Beans can be added to meals as a low salt and low fat protein source.

Finally, don't forget about your snacks and drinks. Chips taste great, but they are loaded with fat, carbs and salt. Popcorn, unsalted pretzels, graham crackers, carrot sticks, apple slices, blueberries and red bell peppers are better choices. Avoid drinks that are high in sugar and fat. Water is a top choice for your body along with low fat milk or milk substitute, naturally flavored water, and low or no sugar added green tea.

For further resources and recipes, try these websites:

kidney.org/nutrition

niddk.nih.gov/health-information/kidney-disease/chronic-kidney-disease-ckd/eating-nutrition

kidneyfund.org/living-kidney-disease/healthy-eating-activity/kidney-friendly-eating-plan



COOKING HEALTHY

GREEN BEANS AND MUSHROOMS

Ingredients:

- 1-10 ounce package of frozen green beans
- 2½ tablespoons margarine
- 1 teaspoon lemon juice
- Pepper to taste
- 1 cup fresh slice mushrooms

Directions:

1. Cook green beans in boiling water for 15 minutes
2. Drain, add 1½ tbsp. margarine, lemon juice and pepper
3. Saute mushrooms in 1 tbsp margarine
4. Toss green beans with mushrooms and serve

Makes 4 servings

Nutrition: 70 calories, total fat: 4.5gm; sodium: 40 mg; total carbohydrate: 6gm; fiber: 2gml protein: 2gml potassium: 195 mg

*Creative Cooking for Renal Diets; Cleveland Clinic



FRUITS AND VEGETABLES

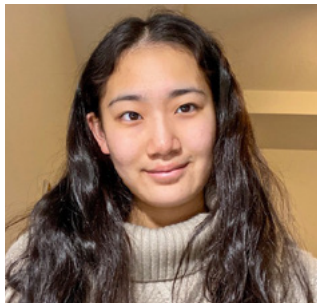
(*limit to 1-2 total servings per day)

- | | |
|-------------------------------------|-------------------|
| Asparagus* | Apples* |
| Bell Peppers | Applesauce |
| Broccoli* | Blackberries* |
| Cabbage | Blueberries |
| Carrots* | Cherries* |
| Cauliflower* | Cranberries |
| Celery, raw* | Grapes* |
| Corn | Lemon |
| Cucumber | Lime |
| Eggplant* | Mandarin Oranges* |
| Greens | Mango* |
| Lettuce | Peaches* |
| Mixed vegetables,
frozen, boiled | Pears, canned |
| Okra | Pears, fresh* |
| Onions* | Plums* |
| Peas* | Raspberries* |
| Spinach, Kale* | Squash* |
| Sprouts (alfalfa and bean)* | Strawberries* |
| Zucchini* | |



Your Kidneys and Your Genes

Margaret Hu, Xiangling Wang, MD



What are genes and mutations?

Genes are hereditary units found inside the cells of our bodies that are passed down to us from our parents. They contain information that dictate our traits, including physical characteristics such as eye color, hair color, or height, and also influence characteristics such as our bone structure and metabolism. Genes contain instructions to make proteins, which are the building blocks of our bodies. Proteins facilitate processes essential to life. Sometimes, a problem occurring within a gene prevents it from making the correct protein, which means the protein does not do its job correctly. This is called a gene mutation. If a mutation prevents an important protein from doing its job, illnesses can develop. For example, a protein called polycystin-1 is important for kidney development and function. Mutations in polycystin-1 can cause polycystic kidney disease.

Genetic kidney diseases

Genetic kidney diseases account for about 10% of chronic kidney disease cases in the United States (Reference 2, Connaughton, Monogenic causes of chronic kidney disease in adults, 2019, page 7, Discussion, paragraph 1, lines 6-7)², presented with cystic kidney diseases, glomerular diseases, electrolyte disturbances, early onset kidney stones or nephrocalcinosis, and congenital anomalies of kidneys and urinary tract (Reference 4, Renal Genetics Program: The Beginning and the Future, 2020, paragraph 6)^{2,4}. Genetic kidney diseases are often identified through genetic testing, which can be ordered by your physicians or providers such as genetic counselors. The cost of genetic testing has significantly decreased in recent years.

Why is it important to identify whether your kidney disease is caused by problems in your gene(s)?

There are several benefits to determining whether a patient has a genetic kidney disease. First, diagnosing a genetic cause could lead to more efficient disease management. A recent study found that 69% of patients identified to have a genetic kidney disease received a new or changed diagnosis, 39% of whom had significant adjustments in their treatment approaches (Reference 3, Tan, Renal Genetics Clinic: 3-year experience in the Cleveland Clinic, 2023, page 1, Results, column 2, lines 13-16)³.

Second, finding a genetic basis for kidney disease is important for patients' family planning and can help them decide on testing for at risk family members. Because genetic diseases could be passed onto children, knowledge of the genetic cause could impact a patient's decision to have children or provide them with information on their child's risk for kidney disease. Third, genetic testing provides information to better select living donors when patients need a kidney transplant. Because the donor is often a first or second-degree relative of the recipient (Reference 1, Caliskan, Evaluation of Genetic Kidney Diseases in Living Donor Kidney Transplantation: Towards Precision Genomic Medicine in Donor Risk Assessment, 2022, page 2, Introduction, paragraph 2, lines 7-8)¹, it is important to ensure the donor does not have the same genetic kidney disease as the recipient. Furthermore, knowing the genetic cause for kidney disease may bring patients opportunities to participate in clinical trials of new therapeutic measures.

Conclusion Genetic kidney diseases are not uncommon. Genetic testing has become increasingly accessible and affordable in recent years, and patients can communicate with physicians or other providers about their options. A referral to a genetics clinic can be made for thorough evaluation and counselling if there is any suspicion for a genetic kidney disease (Reference 4, Renal Genetics Program: The Beginning and the Future, 2020, "A growing program" section, paragraph 8, lines 1-2)⁴.

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4. Renal Genetics Program: the beginning and the future. Consult QD. <https://consultqd.clevelandclinic.org/renal-genetics-program-the-beginning-and-the-future/>



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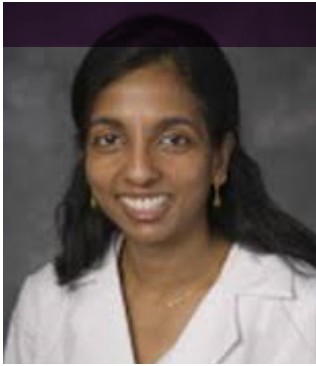
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Heart and Kidney Disease

Aparna Padiyar, MD

Not many people realize the heart and kidneys talk. In fact, they rely so much on each other, if one is not working well it is common for the other to not work as well. One out of three times people with heart failure will have kidney disease¹. And each increases the risk of the other, that is, the risk of heart failure increases the risks associated with kidney disease. It is important for people with heart failure and kidney disease to have both a cardiologist and nephrologist jointly managing their condition.

Many of the treatments for patients with heart failure may have special risks in patients with advanced kidney disease. And many of the medications to treat the heart are filtered by the kidneys and are affected by dialysis. Decision making should be shared jointly between the patient and their doctors.

The presence of heart failure impacts how patients can tolerate dialysis, and what modality may be best². The heart does the best with low rates of fluid removal, so adhering to a low

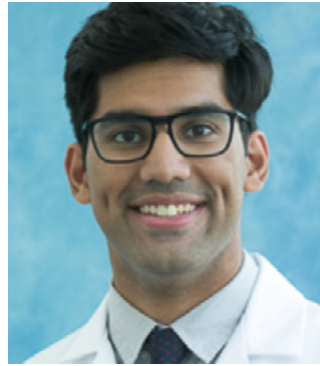
salt, fluid restricted diet is important. Some patients benefit from increased frequency or length of dialysis, using night time programs or frequent home dialysis. Peritoneal dialysis is another option to limit rate of fluid removal,

Certain medications are filtered with dialysis, so if possible medications not effected by dialysis are preferred³. Hypertension can effect both kidney and heart health, so blood pressure monitoring is important. The most accurate measure of blood pressure control in patients on dialysis is blood pressure on the morning after dialysis⁴. Taking these readings into your cardiologist and nephrologist can help better manage your medications.

Medications commonly prescribed to strengthen your heart can also cause high potassium levels in patients with advanced kidney disease³. High levels of potassium can cause issues with your heart's electrical system, and lead to dangerous rhythm problems. A low potassium diet can help you to tolerate your heart medications. There are resources available by the National Kidney Foundation that can help. Also you could discuss referral to a nutritionist with your doctors. There medications are available to help lower your blood potassium levels—talk with your doctors about what is available.

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The Basics on Inherited Kidney Disease

Manan Raina and Nikhil Nair

An inherited kidney disease is one which is passed down from family members. There are 100s of different diseases that can lead to kidney disease but the majority of them are very rare. It is important to know your children's risk of inherited kidney disease as it can lead to kidney failure and damage to other organs of the body. Understandably, if you know you have a history or discover you have a history of kidney disease, one would want to know the risk they can pass it on to their children or develop symptoms later in life. Just because someone has a risk of developing kidney disease does not mean they will develop it and likewise even if someone does not have a history of kidney disease, it does not mean they can't develop it. Other health problems such as diabetes and obesity can increase one's chance of developing these conditions and also increase the bad effects they have. Additionally, two people in the same family can have the same disease but have different severity of the symptoms. There are not always good ways to predict the progression of the disease but early intervention and treatment can improve the prognosis for all of these types of diseases.

To figure out the risk of getting a disease, one can see a genetics professional to look at recent family history and get a genetic test to help determine risk. Having family members with an inherited disease can lead to

an increased risk of a future pregnancy. Inherited Kidney diseases are caused by changes to the genes in your body and can either be passed down from a parent or it can randomly mutate when the baby is developing. There are two sets of genes that come from parents and diseases may have different "inheritance patterns" that influence the risk of them developing. Recessive diseases need two copies of the mutated gene, one from each patient, for the disease to develop. Those with one copy can be carriers who don't have the disease but can pass it down to their children. Some diseases are passed in a dominant fashion with only one gene needed to be passed down to give the disease. While family history is the biggest risk for hereditary kidney disease, other conditions such as diabetes, high blood pressure, and heart disease can speed up the development of disease and lead to more complications. For any given chance/risk of passing on a condition down, it will apply equally to each pregnancy, and having one child with a disease does not increase the chance of having another child with the disease. A couple with autosomal recessive disease has a 25% chance of passing their disease down since they need two copies of the mutated gene, while couples with autosomal dominant diseases have a 50% of passing down their disease since only one mutated gene is needed to pass on the condition.

Next Steps and Resources:

ADPKD: (kidney.org/atoz/content/polycystic)

Alport Syndrome: (kidney.org/atoz/content/alport)

Bartters Syndrome: (rarediseases.info.nih.gov/diseases/5893/bartter-syndrome)

Cystinosis: (rarediseases.info.nih.gov/diseases/6236/cystinosis)

Fabry disease: (kidney.org/atoz/content/fabry)

FSGS: (kidney.org/atoz/content/focal)

Gitelman syndrome: (rarediseases.info.nih.gov/diseases/8547/gitelman-syndrome)

Nephronophthisis: (kidney.org/atoz/content/inherited-kidney-disease)

Thin Basement Membrane Disease: (kidney.org/atoz/content/thin-basement-membrane-disease)

Tuberous Sclerosis Complex (TSC): (ninds.nih.gov/tuberous-sclerosis-fact-sheet)

Check the table on the next page for helpful information and features of common inherited kidney disease!

Disease	Inheritance Pattern	Age of Onset	Clinical Features
ADPKD	Autosomal Dominant	30-40 years	The most common symptoms of ADPKD are kidney cysts, pain in the back and the sides, and headaches. Non-Kidney features include liver cysts, Urinary tract infections, high blood pressure, and kidney stones.
Cystinosis	Autosomal Recessive	Birth to 65 years	Common symptoms include vision impairment, high blood pressure, malabsorption, intellectual disability, difficulty speaking, and movement issues.
Alport Syndrome	X-Linked, Autosomal Recessive and Autosomal Dominant forms.	3-4 years of age	Common symptoms include hearing problems visual issues, blood, and protein in the urine, and kidney failure.
Fabry's disease	X-Linked	Before the age of 10	Common symptoms include heart disease, visual problems, burning sensation of the skin, and inability to sweat.
Gitelman syndrome	Autosomal recessive	2-11 years	Common symptoms include electrolyte loss, fatigue, thirst, muscle cramping/weakness, numbness, low blood pressure and heart palpitation.
Tuberous sclerosis complex (TSC)	Autosomal Dominant	Usually from Birth to 30 years of age	Common symptoms include seizures, intellectual disability, developmental delay, skin changes blood and protein in the urine. Lung and brain issues can arise from the development of tumors.
Thin basement membrane disease	Autosomal Dominant	1 year to 86 years	Common symptoms include blood and protein in the urine.
Congenital abnormalities of the kidney and ureteral tract (CAKUT)	Autosomal Dominant	From Birth	Many different symptoms can arise such as only one kidney, smaller than normal kidney, improperly located kidney, and issues with urination.
Bartter's Syndrome	Autosomal Recessive	Between birth and 65 years	Symptoms include loss of electrolytes, muscle weakness/cramping, urination issues, severe thirst, and growth issues.
Focal and Segmental Glomerulosclerosis	Autosomal Dominant or Recessive	18-45 years	Symptoms of this disease include swelling in the legs, ankles, and around your eyes, weight gain, foamy urine, high protein in the urine, and high fat in the blood
Nephronophthisis	Autosomal Recessive	Between 1 year and 19 years	Symptoms of this disease include increased urination, excessive thirst, weakness an tiredness. This can also cause the development of cysts, fluid-filled sacs, in the kidneys and low blood levels.



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Today, there are only 3.5 donors per 100,000 working persons.



LOW COST COMMITMENT

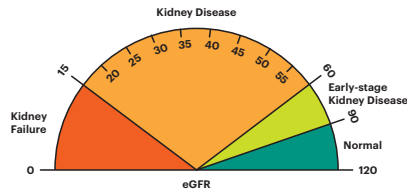
Assuming a median salary of \$60k/year, 80% support for coverage is only \$4,000.

What to expect during the test

A healthcare professional will take a blood sample from a vein in your arm, using a small needle. After the needle is inserted, a small amount of blood will be collected into a test tube or vial. You may feel a little sting when the needle goes in or out. The test usually takes less than five minutes. There are typically no restrictions after blood is drawn for the test.

Results

- eGFR of 90 or higher is in the normal range
- eGFR of 60–89 may mean early kidney disease
- eGFR of 15–59 may mean kidney disease
- eGFR below 15 may mean kidney failure



Understanding your results

There are five stages of kidney disease. Your healthcare provider determines your stage of kidney disease based on the amount of kidney damage shown by your eGFR. Now that you know your eGFR, find out your kidney disease stage in this table to the right.

Kidney disease stage and eGFR

Stage	Description	eGFR	Kidney Function
1	Possible kidney damage (e.g., protein in the urine) with normal kidney function	90 or above	90-100%
2	Kidney damage with mild loss of kidney function	60 to 89	60-89%
3a	Mild to moderate loss of kidney function	45 to 59	45-59%
3b	Moderate to severe loss of kidney function	30 to 44	30-44%
4	Severe loss of kidney function	15 to 29	15-29%
5	Kidney failure	Less than 15	Less than 15%

What to do next

Now that you know your eGFR and your stage of kidney disease, use this table to find questions to ask your healthcare professional at your appointments.

Questions for your healthcare team

If your kidney disease is in stage...						Ask your healthcare professional if you should...
1	2	3a	3b	4	5	
✓	✓	✓	✓	✓	✓	Test your urine for albumin to have a complete picture of your overall kidney health
	✓	✓	✓	✓	✓	Repeat your eGFR test in 3 months to check if your eGFR remains lower than 90
	✓	✓	✓	✓		Take medication that may help slow progression of kidney disease (such as ACE inhibitors, ARBs, SGLT2 inhibitors, or non-steroid mineralocorticoid receptor blockers)
		✓	✓	✓	✓	Adjust any current medications due to reduced kidney function
		✓	✓	✓	✓	Get nutritional and dietary counseling to help support kidney function and overall health
				✓	✓	Start seeing a kidney specialist (nephrologist)
				✓	✓	Learn more about end-stage kidney disease and treatment options
					✓	Be evaluated for a kidney transplant and be placed on a kidney transplant list

For more information, contact the National Kidney Foundation

Toll-free help line: **855.NKF.CARES** or email: nkfcare@kidney.org



KIDNEY.ORG



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YOUR KIDNEYS *and youth*



TEACH KIDS ABOUT

KIDNEY HEALTH

IN THIS NEW, EDUCATIONAL 5-VIDEO SERIES narrated by kidney transplant recipient and “America’s Got Talent” star Angelica Hale, kids will learn about kidney health, nutrition, exercise, biology—and even a little math! All to help them develop habits to keep their kidneys, and the rest of their bodies strong and healthy.



5 VIDEOS

FUN ACTIVITIES

BOREDOM
BUSTERS

[kidney.org/kids](https://www.kidney.org/kids)



NATIONAL KIDNEY
FOUNDATION®



DR. SEDOR



KASSANDRA SPATES-HARDEN

Why Participate in Research: Helping others. Ensuring diversity.

and independent oversight boards of doctors, scientists and community members ensure the well-being of study participants. When you participate in a research study, you help others, maybe even your loved ones, by helping doctors and scientists better understand the causes and impact of kidney diseases or test if a new care solution really improves the health and quality of life for people with kidney diseases. In addition, you may have access to new treatments, which are only available in a research study. And the research study team will carefully monitor your disease and overall health. Finally, of course, you will not be charged for any services or treatments related to the research study.

violations of trust by the medical profession make people of color more hesitant, but not resistant, to participating in medical research studies.

In an effort to make our clinical trial populations more reflective of our kidney disease patient population, we have been purposeful in creating a diverse research team. Representation and relatability are important tools in recruiting minority populations. Hiring coordinators from diverse backgrounds was our first goal. Having regular discussions with the research team on concerns or questions that arise during recruitment efforts, allows us to better tailor our methods and how we talk to patients about research, but more importantly, about kidney diseases in general. Do patients understand the term kidney disease and its' seriousness? Is it better to say kidney failure?

Being purposeful in our recruitment efforts, helped us increase our minority enrollment. There is not one method for increasing minority enrollment in research, but it is imperative that as researchers we explore various methods. A lack of diversity in research is a lack of inclusion in care. And we know people with different ancestries can respond differently to new care solutions. We need research participants that reflect our community to make sure we understand the best use of new approaches for kidney diseases treatment, diagnosis and prevention.

It is time to cure kidney diseases. We need you!

Why participate in research?

Innovation in kidney disease management and treatment has lagged. People with kidney diseases have had few new care solutions, which reduce their burdens and the burdens on those who love and help care for them. However, change has come. Many new drugs and some novel devices are being developed for kidney diseases and kidney failure. But progress (and government regulatory agency approval) is not possible unless people with kidney diseases participate in research studies.

Research studies have multiple goals. Some studies hope to identify what causes a kidney disease; others follow patients to determine how a kidney disease affects people over time. Clinical trials test new ways to prevent, detect or treat kidney diseases and determine if a new test or treatment works. All types of research studies want to understand patients' experiences while participating in the study. Volunteer safety and privacy is really important, and guidelines

The need for diversity.

The increasing diversity within the human population makes the new FDA guidance to increase diversity in research well-timed and of increasing importance. The 2020 U. S. Census shows that while the white population is still the largest self-identified racial or ethnic group, the multiracial population in the US has grown by 276% over the last 10 years.

Black/African American people are 3 times more likely than white people to have kidney failure. Hispanic and American Indian communities also have an excess burden of kidney diseases. Diabetes and high blood pressure are the leading causes of kidney failure among African Americans. Knowing that minorities account for more than 40 percent of the people with kidney failure in the United States, why are most research studies still only recruiting about 5% of minority/diverse populations into clinical trials? History and prior



The Lifesaving Process Of Kidney Paired Donation

APKD

When a patient needs a new kidney, organ donation provides a way for them to receive one and continue living a normal and healthy life afterward.

A new kidney can come from a deceased organ donor or a living donor. However, it can be difficult for some patients to find a new kidney because their bodies need to be a match for the incoming kidney. If the kidney is not a good match, it can be rejected by the body and lead to devastating results.

As a patient waits for a new kidney, sometimes a family member or friend is willing to donate their kidney to them. However, it is common that their kidney would be a better match for a different patient who also needs a kidney. When a patient and willing donor do not match, they are called an incompatible pair.

This is where a process known as kidney paired donation (KPD) can still help the patient find a match. The incompatible pair is entered into a matching software and the process begins. How it works:

- 1) Patient (1) and donor (1) are entered into a kidney matching software
- 2) Patient (2) and donor (2) are also entered into a kidney matching software
- 3) It is determined that donor (1) is a good match for patient (2), and donor (2) is a good match for patient (1)
- 4) Donor (1) donates their kidney to patient (2)
- 5) Donor (2) donates their kidney to patient (1)

By doing this, two patients can receive new kidneys, whereas before neither one of them could find a transplant.

Paired Donation Chains

KPD can also work by creating what are known as paired donation chains. These chains allow for three or more patients to receive a kidney at once. The same process applies:

- 1) Patients (1), (2) and (3) are entered into a kidney matching system along with donors (1), (2) and (3)
 - 2) Donor (1) donates to patient (2)
 - 3) Donor (2) donates to patient (3)
 - 4) Donor (3) then donates to patient (1)
- Now, three patients have new kidneys.

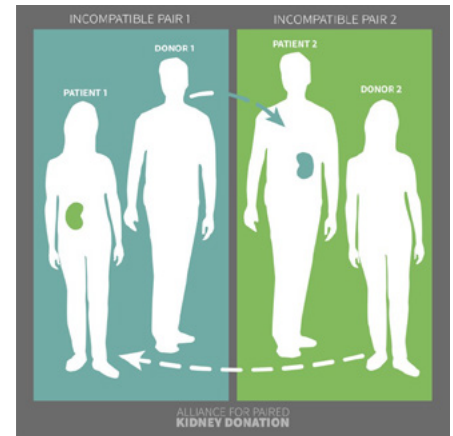
It should be noted that a deceased donor can be used to help complete a paired donation chain. The deceased donor's kidney is often used to start a chain. However, this can be challenging to coordinate because a kidney can only last for a short period of time outside of the body.

KPD can also take place across long distances. Once a kidney is surgically

removed for transplantation, it can be transported to another location where a patient is waiting.

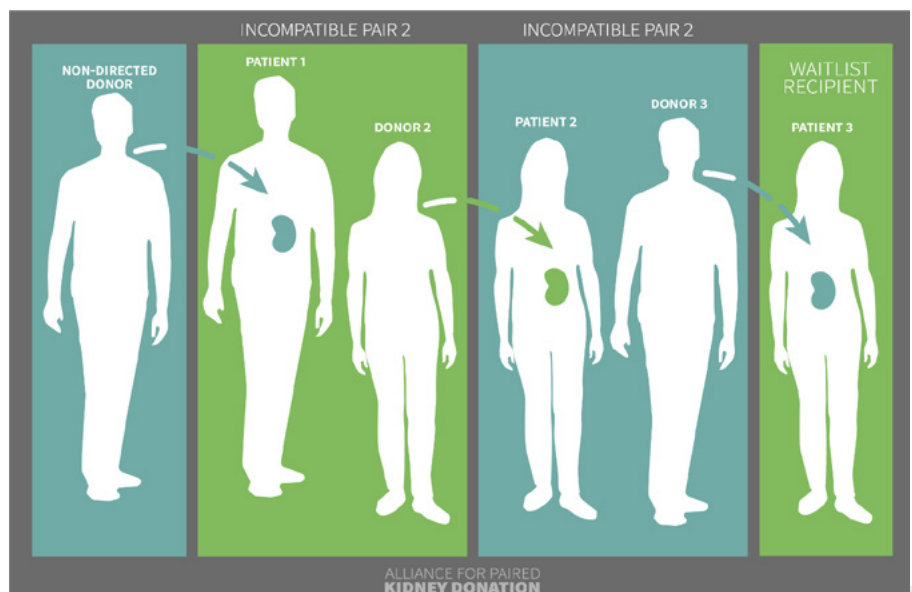
Saving more lives

KPD has helped save more lives than ever before. The process helps take patients off the donation waiting list and provides hope to those who are waiting.



To learn more

about Kidney Paired Donation and resources for those considering living donation, visit The Alliance for Paired Kidney Donation at paireddonation.org.





Protein in the Urine: What, Why & How

Ron Flauto, MD

Every person has protein in their blood stream. There are several different types of proteins in the blood. The most abundant protein in the blood is called albumin. Commonly, “protein” and “albumin” are used interchangeably by medical professionals. Albumin is important because many vital substances, including but not limited to numerous enzymes and medications, are transported in the blood stream with the help of albumin. It also helps keep the fluid in the blood from leaking out of the blood vessel into the tissues. The leakage of fluid into the tissues is called edema. By blood tests, both the amount and the various types of protein can be measured. While all the proteins in the bloodstream are important, the focus will be on albumin.

In a healthy person, the liver makes and sends albumin into the bloodstream. Meanwhile, the kidneys filter all the blood in the body more than 20 times in a day, including all the protein in the bloodstream. From this blood filtration, through a complex mechanism, urine is made. Normally, the albumin stays in the bloodstream, and there is little or no albumin in the urine. Protein in the urine (proteinuria) or albumin in the urine (albuminuria) can arise from kidney disease or damage and results

in albumin depletion from the body. This is important because protein in the urine may not only be a sign of kidney disease, if left unaddressed, it contributes to a decline in kidney function.

Unfortunately, many people do not know if they have proteinuria as there are few signs or symptoms associated with it. However, important indicators to look for may be swelling (edema) in the legs or urine that is described as bubbly, foamy or appears like soap suds in the toilet. To heighten the awareness of kidney problems, it is important to know that diabetes, high blood pressure, ongoing kidney disease and/or a family history of kidney disease increase the risk.

Proteinuria can be confirmed by various tests on the urine. The most common way is called a dipstick urine test, where the patient urinates into a cup; then the lab inserts a paper tab into the urine. When read at a specific time interval, it can estimate the amount of proteinuria. Dipstick urine tests are available at most pharmacies without a prescription. There are more complicated tests which produce the exact amount of proteinuria, but these require a physician’s order.

In summary, proteinuria is not only an indicator of kidney damage or disease, but its presence also leads to a loss of kidney function. If someone suspects that they have proteinuria, they should see their physician as there are important next steps. The physician will try to figure out why there is proteinuria

with additional blood and urine tests, and maybe a kidney biopsy. Depending upon the cause, specific medications can be started. Blood pressure control and diet are commonly used to help reduce proteinuria and, therefore, preserve kidney function.

I recommend the following websites:

niddk.nih.gov/health-information/kidney-disease/chronic-kidney-disease-ckd/tests-diagnosis/albuminuria-albumin-urine

kidney.org/search-results?solr-keywords=protein+in+urine



Raising Children in a Family with Inherited Kidney Disease *Dr. Christina Nguyen*

There is great stress on loved ones when a family member has chronic kidney disease. When the type of kidney disease can be passed on to children, there is an added challenge. There are a lot of feelings and beliefs on how to approach raising children who may be at risk of having an inherited kidney disease. The how and when to discuss an inherited disease with a child is a family's decision. There are strategies that can promote physical and emotional health for at risk children as they grow up to prepare them for living a kidney conscious life.

Resources:

1. National Kidney Foundation: Helping Children Adjust When a Parent Has Kidney Failure. kidney.org/atoz/content/questionschildren
2. Book: "Logan's Bumpy Kidneys" by April Cielica. resources.pkdcure.org/resource/logans-bumpy-kidneys
3. Coloring Book: "Annie has Alport Syndrome" Alport Syndrome Foundation alportsyndrome.org/about-alport-syndrome/asf-coloring-book

- Mirror the behaviors related to health care that you want your child to exhibit as they get older. Show the child that **you value your health** and your health is part of day to day life. Go to appointments, show that you take your medications, or explain food choices you make.
- Encourage an **active, healthy** life. Excess weight gain over the course of life lead to health problems (e.g. high cholesterol, high blood pressure, diabetes) that stress the kidney beyond any underlying kidney disease. Find ways to exercise as a family. This can be as simple as walking.
- **Start a healthy diet** early in life. A diet rich in fruits and vegetables can help with cholesterol. High salt consumption increases the risk for high blood pressure, a common complication of kidney disease. Eating habits start to develop as a baby and are difficult to change as you get older.
- It is good to **share your fears and feelings** about having a kidney disease when you are ready. Knowing that a loved one is scared, tired, stressed, etc will promote the child sharing his/her feelings with you. This open communication promotes honesty and mental health as your child learns more about a potential disease.
- **Start education about what the kidneys do** and why they are important. Talk to your child's, your doctor, and/or disease specific foundations about age appropriate education resources.



How Providers Can Help Improve Kidney Health among LGBTQ+ Patients *Ramona Peel*

The LGBTQ+ community in the U.S. has doubled over the last decade and become more visible as a patient population. However, LGBTQ+ patients are much more likely than others to suffer from chronic health issues, including kidney disease. This is because LGBTQ+ people are more likely than others to develop conditions such as diabetes, high blood pressure, and heart disease which increase their risk of kidney disease. Unequal health risks are related to the experiences of living in communities and environments that exclude or even discriminate against LGBTQ+ people. We call this kind of stress “minority stress.” In many areas of public life, such as healthcare, anti-discrimination laws for sexual orientation or gender identity remain lacking at the federal and state levels. What’s more, LGBTQ+ people face barriers to healthcare: Researchers have shown that this community is more likely to be unemployed and live in poverty, and less likely to be insured. During healthcare appointments, many LGBTQ+ patients report having adverse or even hostile encounters. Many avoid sharing their sexual orientation or gender identity with their healthcare providers, fearing judgment and remembering past negative experiences.

So how can providers support their LGBTQ+ patients and help them achieve better kidney health? Many negative interactions start with incorrect assumptions about a patient’s sexual orientation or gender identity. A good place to start: Use gender-neutral language (you can greet groups as “folks” rather than “ladies and gentlemen”), sharing your gender pronouns to show that you are inclusive (such as “Hi, my name is Ramona and my pronouns are she/her”), and addressing patients by the names and pronouns they use for themselves – even when that name is different from what you see on the patient chart! Small changes in your physical clinical environment can also make a big difference. Consider displaying symbols such as the rainbow Pride flag and labeling single-occupancy restrooms as “all-gender.”

Change how you ask questions on intake forms that are more LGBTQ+-inclusive. For example, instead of asking a single question about “sex” with the only options being male or female, ask about gender identity while providing multiple options - and allow patients to describe their gender identities in their own words. Most importantly, provide training to your staff (clinical and frontline) so they can learn to contribute to a truly welcoming climate for all patients. The results are worth it: When you make your clinical space more inclusive, you can do your part to reduce minority stress for LGBTQ+ patients and improve both their overall and kidney health! Remember: Inclusion is a journey. And you can be the driver of better health for your LGBTQ+ patients. Start making small changes today!

Further Reading:

Improving the health care of lesbian, gay, bisexual and transgender people: Understanding and Eliminating Health Disparities, The Fenway Institute, 2016 <https://www.lgbtqihealtheducation.org/publication/improving-the-health-care-of-lesbian-gay-bisexual-and-transgender-lgbt-people-understanding-and-eliminating-health-disparities>

Older LGBT+ Adults Have Higher Rates of Kidney Disease than Heterosexual Peers, NORC at the University of Chicago, 2023 <https://www.norc.org/NewsEventsPublications/PressReleases/Pages/older-lgbt-adults-have-higher-rates-of-kidney-disease-than-heterosexual-peers.aspx>

Discrimination Prevents LGBTQ People From Accessing Health Care, Center For American Progress, 2018 <https://www.americanprogress.org/article/discrimination-prevents-lgbtq-people-accessing-health-care>

Learn About Primary Hyperoxaluria Type 1

Primary hyperoxaluria type 1 (PH1) is a rare, inherited disease that causes the overproduction of oxalate

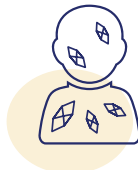


What are the common signs of PH1?

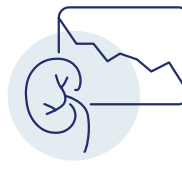
Although kidney stones are the most common, and often the first sign of PH1, not all people with PH1 will have stones. When you have PH1, your kidneys are at risk for damage even if you are not getting stones. In fact, PH1 may present in a number of ways, including but not limited to:



Crystal deposits in the kidneys known as nephrocalcinosis



Crystal deposits in other organs including the eyes, bones, skin, heart, and central nervous system



Kidney Failure



Failure to thrive in babies

Having one of these signs or symptoms does not necessarily mean that you or a loved one have PH1. Your doctor is your most important source of information if you ever have questions about your health.

Visit [TakeOnPh1.com](https://www.TakeOnPh1.com) to Learn More



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Horizon is proud to support the National Kidney Foundation of Northern Ohio.

Horizon is a global biotechnology company focused on the discovery, development and commercialization of medicines that address critical needs for people impacted by rare, autoimmune and severe inflammatory diseases. Our pipeline is purposeful: We apply scientific expertise and courage to bring clinically meaningful therapies to patients. We believe science and compassion must work together to transform lives.



horizontherapeutics.com

NKF NATIONAL RESOURCES



Get help navigating the challenges of kidney disease, organ donation and transplantation. **1.855.NKF.CARES (1.855.653.2273)**
nkfcares@kidney.org



You're Not Alone! Talk to someone who's been there. Speak with a trained peer mentor who can share their experiences about dialysis, transplant or living kidney donation with you. Call **855-653-7337 (855-NKF-PEER)**
kidney.org/patients/peers



BABG program leads to a conversation that can save a life. Whether you need a kidney or are considering donation, let us help you start the conversation. **kidney.org/transplantation/livingdonors**



Join our network of advocates to make a difference for kidney patients. You can influence public policy relating to kidney health, organ donation, and transplantation through simple activities like emailing, calling, or tweeting your legislators. For more information: **advocacy.kidney.org**



The NKF Patient Network is a patient registry for people at all stages and with all types of kidney disease. As part of the Network, you help research by answering survey questions about your experience with kidney disease. **kidney.org/nkfpatientnetwork**



Northern Ohio Community Resources:

AFFORDABLE COMPUTERS AND INTERNET: PCs for People provides affordable computers and low-cost internet to eligible individuals and nonprofits. 216-930-5741.

pcsforpeople.org/ohio

BEREAVEMENT SERVICES: Hospice of the Western Reserve provides support groups, education, training, individual grief support, and crisis response. Main line: 800-707-8922. Grief Services: 216-486-6838. **hospicewr.org**

COMMUNITY AGENCIES:

Cuyahoga Job and Family Services provides access to jobs, benefits, and community services. Services include Medicaid, food, cash, job, and childcare assistance. 216-881-5554. **cjfs.cuyahogacounty.us**

Step Forward: supplies assistance for Covid-19, Head Start, energy bills, and personal and professional development for individuals and families. 216-696-9077.

stepforwardtoday.org

Western Reserve Area Agency on Aging provides support services for older adults, persons with disabilities, and caregivers; ombudsman, PASSPORT, Cares Act, assisted living waivers, and helps with nutrition and food security. 216-621-0303. 800-626-7277.

areaagingsolutions.org

FOOD SERVICES:

Hunger Network of Cleveland provides food and linkages to vital services for the hungry. 216-619-8155. **hungernetwork.org**
email: **Help@HungerNetwork.org**.

Greater Cleveland Foodbank supplies hunger relief, community food distribution, and connects clients to other non-profits for housing, healthcare, and employment needs. 216.738.2265.

greaterclevelandfoodbank.org

Akron-Canton Regional Foodbank provides food and essential items to members of hunger-relief programs in Carroll, Holmes, Medina, Portage, Stark, Summit, Tuscarawas, and Wayne. 330-535-6900. **email: info@acrfb.org akroncantonfoodbank.org**

HEALTH AND HUMAN RESOURCES:

*Care Alliance Health Center provides high-quality, comprehensive medical and dental care, patient advocacy, and related services regardless of the ability to pay. 216-535-9100.

carealliance.org

DOVE's goal is to find, educate, screen and support prospective living donors and then match those donors to a Veteran awaiting transplant. 551-449-8319.

email: info@dovetransplant.org

United Way 211 addresses immediate needs of those in crisis and long-term solutions to break the cycle of poverty. Dial 2-1-1.

211oh.org unitedwaycleveland.org

HOUSING SERVICES:

The City Mission provides basic needs, critical recovery resources, and homeless shelters. 216-431-3510. **thecitymission.org**

Cuyahoga Metropolitan Housing Authority (CMHA) provides eligible low-income individuals and families quality, safe, affordable housing in Cuyahoga County. 216-348-5000. **cmha.net**

KIDNEY PATIENT SERVICES:

American Kidney Fund provides financial assistance, kidney screenings, education, clinical research, advocacy, and Kidney Action Day for communities. Kidney Helpline: 866-300-2900.

kidneyfund.org

Beacon Charitable Pharmacy supplies prescription medication assistance and education for residents of Carroll and Stark counties. 330-445-1087. **beaconpharmacy.org**

Kidney Foundation of Ohio helps with medication, transportation, insulin, emergency grants, education, medical alert bands, and community programs. 216-771-2700.

kfohio.org email: info@kfohio.org

LEGAL SERVICE: Legal Aid Society of Cleveland provides legal services at no cost to low-income clients in Ashtabula, Cuyahoga, Geauga, Lake, and Lorain counties.

English: 216-687-1900. Spanish: 216-586-3190. **lasclev.org**

MENTAL HEALTH SERVICES: NAMI Ohio provides advocacy, education, support, crisis intervention, and help for families.

Linkages to Ohio regions. 1-800-686-2646. **namiohio.org**

email: namiohio@namiohio.org

SUICIDE PREVENTION LIFELINE: provides 24/7 free and confidential support. 800-273-TALK (8255).

suicidepreventionlifeline.org

TRANSPORTATION SERVICES: Wings Flights of Hope helps people in need of free air transportation for medical and humanitarian purposes. 866-61-WINGS (94647).

wingsflight.org

UTILITIES ASSISTANCE:

Cleveland Department of Water offers discounted rates through Water Affordability and Homestead Discount.

216-881-8247. **clevelandwater.com/customer-service/water-rates/discount-programs**



NATIONAL KIDNEY
FOUNDATION.



VOICES[★]

FOR KIDNEY HEALTH™

The Sound of Change.

Change starts with you. A nationwide community of people affected by kidney disease is coming together to create change and you can help. Join Voices for Kidney Health, a community of patient and health professional advocates working with elected officials and public leaders to create big solutions to help everyone facing the challenges of kidney disease.

- ★ Protect living donors
- ★ Expand access to home dialysis
- ★ Advance healthcare equity
- ★ Spur investment in prevention and research

Join us [voices.kidney.org](https://www.voices.kidney.org)

UPCOMING EVENTS

KIDNEY WALK

We are excited to be walking together once again for the 2023 Cleveland Kidney Walk on Sunday, June 11 at 8:30am at the Great Lakes Science Center in Cleveland Ohio and we hope you walk with us! By participating in the Cleveland Kidney Walk you'll let others know they're not alone. Together, we'll come together with a common purpose and walk for those who can't. Caring knows no distance; one simple step can change a life. Register for FREE today! kidneywalk.org/cleveland

KIDNEY WALK

Are you located in Northwest Ohio? Then join us for our 2023 Toledo Kidney Walk on September 17, 2023 at the University of Toledo - Centennial Mall. 2801 Bancroft St., Toledo, OH 43606. You can register for this event for FREE! Please contact our **Development Manager, Maddi Snyder** at madalynne.snyder@kidney.org or 440-985-0114



The 2023 NKF Konica Minolta Golf Classic will be on Wednesday, July 26, 2023, at Firestone Country Club. Are you a golfer interested in getting together a foursome, or know a company that may be interested in sponsoring this event? Then please contact our **Development Manager, Maddi Snyder** at madalynne.snyder@kidney.org or 440-985-0114



Do you like comedy and supporting a good cause? Then join us for our KomedY for Kidneys event on Thursday, November 9th at Pickwick and Frolic in Downtown Cleveland from 6:30pm-9:30pm. For this event, you can socialize in a fun setting with industry leaders, medical champions, legislative pioneers, and community advocates, while raising awareness about kidney health. We will be having delicious food and drinks available as well as fun entertainment and a raffle with high end items! We are honoring folks in the Northern OH Kidney Community with the Tedd Wiley Volunteer in Leadership Award and NKF's Advocacy in Action Award. After the mission part of our event, we will be ending the night with a comedy show that'll make you laugh your kidney's off! We are going to be featuring some of Cleveland's top comedians. If you're interested in purchasing tickets or being a sponsor of this program, please reach out to our **Development Manager, Maddi Snyder** at madalynne.snyder@kidney.org or 440-985-0114.





Connecting the Lupus Nephritis Community

Bringing Lupus Nephritis Out of the Shadows

Lupus is a serious, chronic autoimmune disease with many complications that affects many different parts of the body. When lupus affects the kidneys, that's called lupus nephritis. **About 50% of people living with lupus may go on to develop lupus nephritis.**

The kidneys are vital organs, and the damage lupus nephritis causes to them can be permanent. If left untreated, it can lead to kidney failure, which could mean dialysis or a kidney transplant.

That's why it's important to stay informed and maintain regular doctor visits. We invite you to join the ALL IN™ community and register for a free ALL IN™ for LN Awareness Kit, filled with important information about lupus nephritis to help you prepare for conversations with your doctor.

Visit www.allinforln.com to learn more.

Together, we can raise awareness and offer support.
There is strength in community.



Jasmine, diagnosed with lupus nephritis in 2018.

For more information about lupus nephritis visit www.allinforln.com
To join the ALL IN™ community and receive your LN Awareness Kit visit www.allinforln.com/register

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Kidney Health Begins with Kidney Smart®



Take control of your kidney health.

Instructor-led online and telephonic classes are taught by kidney care experts. You can easily ask questions similar to if you were in an in-person class setting.

More than 200,000 people have taken the next step in kidney education by attending a Kidney Smart class.

Visit KidneySmart.org for more information.



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Go from **zero** to **kidney smart**

in less than 3 minutes



Most people don't know how vital their kidneys are. Learn about the importance of your kidneys and how to take care of them in this short video!

WATCH AND SHARE



[Kidney.org/YourKidneysAndYou](https://www.kidney.org/YourKidneysAndYou)



ONLINE COMMUNITY FOR
**PARENTS of
CHILDREN with
KIDNEY DISEASE**

You're not alone. The National Kidney Foundation's online community is a safe and supportive space where you can share your experiences, ask questions, and get answers that are accurate and up-to-date. Connect with other parents today!



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 us is that you can network anonymously and connect with other parents who are affected by kidney disease.



NATIONAL KIDNEY
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healthunlocked.com/nkf-parents