



Patient Engagement & Advocacy Guide



THE NATIONAL **KIDNEY** FOUNDATION

Dear Advocate:

Welcome to The National Kidney Foundation (NKF) Voices for Kidney Health Patient Engagement & Advocacy Guide

We value your commitment to empowering and educating others about chronic kidney disease (CKD), as well as affecting change through policy and legislation. Voices for Kidney Health advocates write directly to Congress and to newspapers, visit Members of Congress in Washington, D.C. and their district offices, and share information about our kidney policy campaigns with their friends and family on social media. You may also be active in raising awareness in your communities, lending your voice to advisory panels or boards, and participating in focus groups to ensure the kidney patient story is incorporated into our program, policy, and treatment-related decision making.

As the nation's leading kidney advocacy organization, NKF aims to improve awareness, prevention, and treatment of kidney disease at the federal, state, and community levels. It is YOU who are key to achieving the advocacy goals integral to our mission.

This guide will serve as a reference for when you interact with your elected officials and other policymakers in your community. In the following pages, you will find advocacy resources as well as key statistics and other information on kidney disease. But remember, it's your personal experiences with kidney disease that are your most powerful tool. Your personal story is the most effective way to make an impact with elected officials and their staffs. In this guide you will find guidance on how to deliver that story with the greatest possible impact.

We look forward to seeing where your advocacy takes you and being with you every step of the way!

Thank you again for your dedication to the kidney community!



Kevin Longino
Chief Executive Officer of NKF and Kidney Transplant Patient

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THE NATIONAL **KIDNEY** FOUNDATION

The National Kidney Foundation is committed to encouraging, educating, and empowering people affected by CKD, dialysis, kidney transplantation, and organ donation to be their own best advocates.

The National Kidney Foundation's Voices for Kidney Health is a community of patients and care partner advocates working with elected officials and other public leaders to help those facing the challenges of kidney disease and promote better kidney health nationally. Voices for Kidney Health advocates for policies that will help prevent and delay kidney disease, ensure quality care for patients with kidney failure, and make certain that everyone who wants a transplant can get one.

We look to you, as one of NKF's Voices for Kidney Health advocates, to be a leader in your community. Motivate others to get involved in advocacy work; share our best practices, tools, and resources with them. Help us build an even stronger grassroots presence in every part of the country.

Expanding our reach helps us bring greater attention to kidney disease as a public health crisis. Raise the bar by pushing our communities and governments to improve policies, practices, and decisions regarding kidney disease, dialysis, transplantation, and organ donation. There is much work to be done—and we need everyone to raise their voice!



PATIENT ENGAGEMENT & ADVOCACY

The NKF Patient Engagement & Advocacy Guide provides information and resources on ways you, as a kidney patient, living donor, practitioner, or family member, can assess, articulate, and pursue the best strategies available for advocating around kidney disease awareness, prevention, and treatment. As an empowered individual, you raise your voice with NKF on behalf of patients and families affected by kidney disease. “Engagement” includes taking an active role to ensure that the values, goals, and preferences of the kidney community are considered in the development and implementation of health policy, treatments, and services. By bringing awareness of challenges faced by those living with kidney disease, you are the voice that helps drive change.

NKF’s advocacy programs consist of advocates representing the full spectrum of kidney disease (e.g. early stage CKD, in-center and home dialysis, kidney transplantation) as well as living kidney donors, family members, care partners, and medical practitioners. The tie that binds them is their desire to make a difference for kidney patients.

This guide offers advice for communicating with legislators, engaging your community, making your voice heard, and ensuring your advocacy is efficient and effective. Use the resources in this guide to support your efforts and to make the most of your advocacy activities.

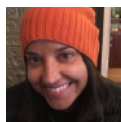
BECOME AN ADVOCATE

Whether it is legislation or policy initiatives involving research funding, protecting access to affordable healthcare, or quality measures of patient care, kidney patients’ lives are affected. NKF is working to help the kidney community engage in effective advocacy. When you become an advocate, you take on a leadership role in NKF’s grassroots advocacy network, consistently speaking out to ensure that policy and programs support what is best for kidney patients and families.

As an Effective Advocate you consistently demonstrate:

- Leadership skills
- Passion and an ability to speak from the heart
- That you can clearly articulate issues and challenges in the kidney community
- That you can craft a unique and compelling personal stories
- Knowledge/interest in public policy process and/or policy issues
- Commitment to long-term involvement
- Understanding of the “bigger picture”
- Desire to help fellow kidney patients

OUR ADVOCATES SPEAK



“I like that there’s a network of involved and committed advocates to learn from and be inspired by.”

Elizabeth Fortune
Arkansas-based advocate



“Are you eager for change in kidney care? Join the NKF Voices for Kidney Health community to advocate to increase kidney disease awareness.”

Dr. Holly Mattix-Kramer, MD.
MPH past NKF President
Illinois-based advocate



“The Voices for Kidney Health community allows me to stand before elected officials and fellow advocates and be a voice for the unheard and underrepresented communities.”

Curtis Warfield
Indiana-based advocate

GETTING STARTED

HOW SHARING YOUR STORY HELPS

Sharing your story with your legislators allows them to understand the reality of kidney disease. Your voice can strengthen relationships with elected officials so that when policies concerning kidney disease cross their desks, they think of kidney patients. You can be their resource for advice on kidney disease policy. Your experience has immense value and meaning.

SHARING YOUR STORY WITH LEGISLATORS

By sharing your story, you put a face on kidney disease and give patients a voice. It becomes real to legislators because you are sharing your struggles and successes. Tell them why the issue is important to you and how it makes a difference to people in your state. The more they understand your situation and challenges, the more likely they are to want to help.

FIRST THINGS FIRST!

Before we dive deeper, let's check to see if you have asked your friends, family, and colleagues to sign up at NKF's Voices for Kidney Health page to email or tweet their legislators? Have you acted by messaging your legislators?

Always thank your legislator or their staff for their time.



QUICK TIPS

on sharing your story

- **Give a brief introduction.** Introduce yourself, then explain the purpose of your visit. Describe the issue or problem you are presenting, and how the legislator can help.
- **Summarize your story.** You will likely have a short time (15-20 minutes) with the legislator or staff. Therefore, focus on key points of your personal experience. Discuss the challenges of living with kidney disease but frame your story in a positive way. Use terms that everyone can understand, since your audience may know little about kidney disease.
- **Plan ahead** and make sure to stay on topic.
- **Remember**—you are not here to discuss partisan politics. You are an advocate for all kidney patients!
- **Ask for their support.** You have identified an issue that is very important to kidney patients. Now provide a solution. Ask if they will co-sponsor or vote in support of a specific bill.
- **Say thank you!** Always thank your legislator or their staff for their time. Let them know that you would like to serve as a resource on kidney disease issues.
- **Legislators and their staff are now used to meeting virtually!** Don't miss this opportunity to connect with them from your own home or office!

WORKING WITH LEGISLATORS

Advocacy should start well before the bill you are concerned about is introduced. A good time to start is when Members and their staff are back in their home districts/states. Set up a meeting with them virtually or at their local office. Legislators and staff are also accessible virtually or in their Washington, D.C. office. Consider visiting your Member of Congress if you are visiting in the nation's capital. Advocacy at the local level, meanwhile, shows constituent support for your issue and carries tremendous weight! Remember, as former Speaker of the United States House of Representatives Tip O'Neill once said, "All politics is local!"

As a constituent and an advocate for individuals and families affected by kidney disease, you can have a significant influence shaping your legislators views and positions as you educate them.



QUICK TIPS

working with legislators

- **Know who represents you.** Learn about your Members' assignments, staff, where their specialties lie, and their professional background prior to being elected to office.
- To be an effective voice for kidney patients, it helps to know where your representatives already stand on CKD policy and related bills. You can find information on NKF Advocacy webpages, and the websites of elected officials and their legislatures.
- **The NKF Advocacy and Policy Website** (kidney.org/advocacy and voices.kidney.org) include links to fact sheets policy and legislation, action pages policy and legislators' contact information.
- **The U.S. Senate** (senate.gov) and the **U.S. House of Representatives** (house.gov) websites include links to webpages for individual Members of Congress, as well as committees.
- **Congress.gov** provides legislative information from the Library of Congress. Check here to see if your legislator is a co-sponsor of NKF-supported legislation!
- **Know your talking points.** When you have the opportunity to speak with a legislator you will likely only have 15–20 minutes. It is important to choose key talking points and requests in advance. Contact NKF for talking points on policy priorities (nkfadvocacy@kidney.org).
- **Get to know key staff.** Most of the time you will meet with congressional staff instead of your Member. The staffers are trusted policy advisors for that legislator. Their opinion and recommendations carry significant weight.

CORRESPONDING WITH LEGISLATORS

EMAIL COMMUNICATIONS

Many constituents find it faster and more convenient to contact their legislators through email. Emails to legislators are a key tool, particularly when sent directly to the legislator or staff. It often may be your best way to share details about kidney disease policy. It can take up to three weeks or more for regular mail to make it to your legislator's office, an email is instant!

The written word is probably the most powerful, convenient, and useful tool available to get your message out. Be brief, specific, and state your purpose up front. The best times to write are when an organization is pushing for the introduction of legislation, after a bill has been introduced, before committee consideration, before a floor vote, and to thank Members of Congress or their staff following a vote, or to thank your legislator for joining as a co-sponsor.

WRITING AN EFFECTIVE EMAIL

SAMPLE EMAIL TO LEGISLATOR

Subject Line: Emphasize the issue you are writing about.

First line: Salutation and the official title of the elected official. (Always double check this.)

First Paragraph: Introduce yourself and briefly explain why you are writing.

Second Paragraph: Expand more on the subject of your email. Be specific. If you are supporting a specific piece of legislation, say so, and explain why it is important to you. Remember to reference your story!

Last Paragraph: Respectfully request a specific action be taken by your Member. This tells your representative what you want and allows you to hold him or her accountable. You may also want to request a meeting so that you can share more about the purpose of your email.

Signature: Include your address and contact information. Providing your address reminds the legislator that you are a constituent.

To: Legislator

Re: Re: Please Co-Sponsor the Early Detection Act (S. 123)

Dear Senator (name),

My name is John Kidney. As a kidney patient, I am writing to request you co-sponsor of the Early Detection Act (S.123) to ensure that your constituents can avoid the devastating effects of kidney disease.

In 2000, I was diagnosed with kidney disease, and in 2004, I received a living donor kidney transplant. This legislation could have helped people, like me, receive my diagnosis earlier when I could have made lifestyle changes to try to prevent my kidney disease from progressing. In many instances, early detection and treatment can slow or even stop the progression of kidney disease.

Please consider co-sponsor the Early Detection Act (S.123) to ensure that your constituents can avoid the devastating effects of kidney disease.

Sincerely,
John Kidney
Address
City, State, Zip
Phone
Email

MEETING WITH LEGISLATORS

FACE-TO-FACE AND VIRTUAL MEETINGS

Another way to make your voice heard as an advocate is to request a face-to-face or virtual meeting with your legislator. A personal visit can be an effective method of getting the attention of legislators and staff. Members of Congress will meet their constituents at either their district or D.C. offices. To find out if your legislator will be in your district or not, use the schedules provided by the House Majority Leader or at [Senate.gov](https://www.senate.gov). Research shows that 77% of congressional staff believe that these meetings have a significant impact on their legislators' decisions.

Virtual meetings are a powerful new option for advocates to utilize. They allow you to speak with the Member or staff from home or your office, eliminating the need for you to travel. When speaking with a scheduler, just specify that you're hoping to meet virtually. Be prepared to download Zoom, Microsoft Teams or a similar program and consider using an NKF background to move any distractions for your fellow participants. Like an in-person meeting, you will need to dress professionally and hold the meeting in an appropriate location to give the best impression. However, be prepared to mute yourself when not speaking and for it to be harder to read your audience on a screen than it would be in person. Please, make sure to ask for permission to take and use a screen shot of your meeting.

House:
majorityleader.gov/floor/#annual

Senate:
senate.gov/reference/Index/Calendars_schedules.htm

REQUESTING A MEETING

First, determine the purpose of the visit. For a meeting or to invite your legislator to an event, request your meeting 3–4 weeks in advance. Don't hesitate to follow up on a request if you don't hear back after a few days. You will then be contacted by a scheduler one to two weeks before the requested date. Contact information for your Member can be found on their official webpage. You should also invite local NKF staff and other advocates to join you.

PREPARING FOR YOUR MEETING

Visit [kidney.org/advocacy/resources](https://www.kidney.org/advocacy/resources) for fact sheets on legislative and policy priorities and the impact of kidney disease in your state to bring to your meeting. Then email nkfadvocacy@kidney.org to let NKF know about your visit. We can help you prepare for the meeting and provide you with useful resources.

FRAMING YOUR MEETING

Remember that the long-term connections you are building are important, so it is necessary to leave a great first impression. Dress and act profession-

ally. Prepare a brief description of who you are, your kidney disease story, your issue(s) and solution(s), and ask for their support. Show the Member and the staff how kidney disease affects constituents in your state. Remember to stay focused, you will likely have only 15–20 minutes for your meeting!

AFTER THE MEETING

Always send a thank you email or letter to reinforce your message. If you met with your legislator, thank them for their help and remind them of the issues you discussed. If you met with staff, thank them and consider writing the legislator to praise the staff you met with. Remember to keep the voice of the email professional. Always be polite, thank them for their time, and provide any additional information that you agreed to get to them. Offer to be a resource for additional information. Be sure to include PDFs of any documents you discussed in the meeting and work with the local NKF staff to invite them to an upcoming NKF event to meet kidney patients and healthcare practitioners! Finally, report your meeting's outcome to NKF at nkfadvocacy@kidney.org!

MEETING WITH LEGISLATORS

SAMPLE FOLLOW-UP LETTER

Today's date

The Honorable (first, last name)
U.S. House of Representatives
Washington, DC 20515

or

The Honorable (first, last name)
United States Senate
Washington, DC 20515

Dear Representative (Last name):

Thank you for taking the time to meet with me on (day, month, year) as a part of the Annual Kidney Patient Summit. I truly enjoyed my experience on Capitol Hill. As we discussed, chronic kidney disease is a potentially life-threatening and life-altering disease, affecting an estimated 37 million Americans, while about 80 million more are at risk for kidney disease due to diabetes or high blood pressure.

[Insert your personal story and background information here.]

I urge you to support [Insert your "asks."] Thank you for considering this request and for taking the time to discuss these very important issues.

Sincerely,
John Kidney,
Address, City, State, Zip
Email, phone #
Phone
Email

TOWN HALL MEETINGS

Town hall meetings are another wonderful way to meet with your legislators and share your message. They can be held in person, on the phone, or via Skype, social media, or other platforms. Sometimes they are by invite only, and other times open to the public.

QUICK TIPS

advocating at a town hall

- Contact your legislator's office, sign up for their mailing list, or visit townhallproject.com to find a meeting.
- Bring friends, fellow patients, or healthcare practitioners, and NKF staff to show a united front. The more the merrier!
- You will likely only get one question or comment, so plan ahead.
- Make sure to mention you are a kidney patient, family member, living donor, or healthcare practitioner.
- Be sure to mention your name and town.
- Be prepared—if the legislator is supporting a bill, please thank them; don't just ask a question!
- Bring fact sheets to leave with the legislator's staff and get their contact information.
- Follow up with the legislator's office by email to thank them for hosting and send them PDF-ed materials.
- Share the experience with NKF at nkfadvocacy@kidney.org so that we can follow up with their office as well!

COMMUNICATING WITH LEGISLATORS

TELEPHONE CONVERSATIONS

Picking up the phone to voice your opinions may seem like a daunting task, but it isn't if you follow these tips.

QUICK TIPS

advocating by phone

- **Preparation:** Before calling, make a list of a 2–3 short talking points. NKF can help you by providing you with those. This will also prepare you to leave a voicemail.
- **Conversation:** When you call a legislator's office, ask to speak with the legislative aide responsible for health policy. If the aide is not available, leave a clear message, including your name, address, and phone number with the person who answers the phone. Be mindful of the fact that a congressional office receives phone calls throughout the day, particularly when a controversial topic is under consideration. Ask for the aide's email to follow up with them.
- **Follow-up:** Be sure to thank elected officials and their staff members for their time. A follow-up email is a good opportunity to restate your position and include additional materials, such as links to a position statement, policy papers, or relevant articles. This also helps establish a relationship with the office.



SOCIAL MEDIA

SOCIAL MEDIA

Most legislators know that social media is a quick and easy way to engage their constituents. Virtually all federal legislators and most state legislators have social media accounts. Whether they or their staff handle their accounts, they do keep tabs on what their constituents are saying. Whereas email excels at passing along details, social media excels at spreading awareness to the public and engaging your legislators through short messages. According to the Congressional Management Foundation, two-thirds of Members of Congress believe it is a valuable tool to reach constituents. Did you know that most Representatives only need 10-20 tweets/posts before they review an issue? How many people can you get to tweet/post?

QUICK TIPS

on social media

- Find more social media tips at voices.kidney.org
- Social media is about attention and conversation.
- Consider sharing and commenting on other people's or organizations' posts. The more you engage with your followers, the more they will understand your message.
- Be genuine and polite. Try not to simply broadcast; rather, speak to others as your friends. This will help grant you credibility as a trusted source.
- Never "flame" or be a "troll"!
- Be reliable. Share quality content from trusted sources and avoid amplifying erroneous messages. Statistics are your best friend!
- Reliability also means posting to your social media services regularly. This helps establish you as an important source of information you as an important source of information and ideas for your community.
- Use eye-catching images to make an impression on those seeing your posts and tweets.
- Make your presence known! Follow your legislators; "like" their pages; "tag" them when appropriate; share NKF's links; and use **#MyKidneyVoice**

The more you engage with your followers, the more they will understand that your priorities are their priorities too.



SOCIAL MEDIA

QUICK TIPS

- “Like” the Facebook pages of your legislators and local NKF office pages.
- Share content from the main NKF Facebook page, **facebook.com/nationalkidneyfoundation**
- When sharing relevant stories to your own wall, be sure to tag your legislators in the post. You can do this by using the “@” symbol before typing their name (or the name of their Facebook page).
- Keep Facebook posts short and conversational, and include an image whenever possible.
- Include links on Facebook to direct people back to the National Kidney Foundation website at **kidney.org** or **voices.kidney.org**
- Ask people to share your content through Facebook.
- Post and comment on your legislators’ pages to ask them to support a policy issue you believe in or to thank them for supporting an issue.

QUICK TIPS

- Follow each of your legislators on Twitter.
- Follow **@NKF_advocacy** to stay informed and share Tweets.
- Share links to NKF press releases, images from events, and other information in 280 characters or less.
- When appropriate, Tweet directly to members of the media and bloggers to encourage them to cover your efforts and help spread the word.
- Tweet directly to Members of Congress with the action you want them to take or to thank them for their support.
- Use hashtags, such as **#MyKidneyVoice**

SAMPLE TWEET: **@[YourREP/SEN]** Once your kidneys stop working, so do you. Support kidney patients and **@NKF_advocacy** by co-sponsoring H.R.3867: **#MyKidneyVoice**

SAMPLE FACEBOOK POST: I’m supporting kidney patients and organ donors with @nkf by urging **@ [YourREP/SEN]** to support the Living Donor Protection Act (bill number) and help protect living organ donors. **#MyKidneyVoice**

SHARING YOUR STORY THROUGH MEDIA

MEDIA OUTLETS: COMMUNICATE YOUR STORY AND SPREAD THE WORD

PRINT

Local newspapers and magazines are examples of print media outlets where you can share your kidney story. Begin by contacting NKF Government Relations, which will work to help you target publications or reporters who recently ran articles on kidney disease, or whose past coverage aligns with your message. Media outlets also have websites that serve as great places to identify reporters and editors, get contact information, and read recent coverage. NKF can help arrange for you to meet with reporters and staff in person to share your story. We can help you, for example, invite the press to an interesting location, such as an NKF-hosted event or your dialysis center. Perhaps the media outlet also has a community calendar to post an NKF event on to help publicize it.

QUICK TIPS

on print media

- **First, contact NKF Government Relations staff** for who will work with NKF Media Relations to provide you with assistance and talking points!
- **Give a brief introduction** in your email to the reporter and briefly explain why your story would be of interest.
- **Be brief.** Keep your communication to the point. Limit your message to one paragraph.
- **Follow-up.** Reporters get many emails each day. If you don't hear from them within two or three days, it is important to follow up. It is ok to follow up with a phone call, but keep your message succinct.



“ When I was on dialysis and my clinic mates were threatened with the loss of healthcare and support, I found a new purpose in my life: to advocate for my fellow kidney patients. ”

*James Myers
Indiana-based advocate*



SHARING YOUR STORY THROUGH MEDIA

PHONE, TV, OR RADIO INTERVIEW

In-person, phone, and Zoom interviews are great media opportunities. If your interview is via Zoom, find a quiet space to conduct it with a background that is either a nondescript wall, bookcase, or a part of your home you don't mind sharing with the reporter and TV audience. Arrive on Zoom 10 minutes early, make sure your audio is on and not muted, make sure your lighting is behind the computer screen, not in front of it and choose an appropriate background that is not distracting. No green screens please, but blurring your background is fine.

Find out what the reporter is seeking and get their deadline. Knowing the goal of the reporter's story allows you to anticipate and prepare for any type of questions. Contacting the media first allows you to take the lead on the direction of the story.

QUICK TIPS

on interviewing

Before the Interview

- First, contact NKF Government Relations staff who will work with NKF Media Relations to provide you with assistance and talking points!
- Become familiar with the media outlet and the reporter's style by reviewing past coverage by the reporter and the outlet.

- Develop and review two or three key messages you want to highlight.
- Anticipate and prepare responses for potential questions.
- *Arrive early.* A journalist's schedule is unpredictable. Arriving early shows you are respectful of their time and allows you to be flexible if changes are necessary.

During the Interview

- Stay on message, particularly if the questions don't directly address the points you want to make. Answer the questions you have knowledge of, but find a way to bridge the conversation back to your main points.
- Be honest. It's OK to say, "Let me follow-up with you on that."

LETTERS TO THE EDITOR AND OP-EDS

Different from an article, these are responses by readers to the paper about an article or to gain attention to a point of view on an issue. These are excellent ways to get your community to pay attention to an issue.

QUICK TIPS

on op-eds and letters to the editor

Letters to the Editor

- First, contact NKF Government Relations staff who will work with NKF Media Relations to provide you with assistance and talking points!
- These are typically short commentaries, around 250 to 300 words.
- They can be in support of or opposition to an article or editorial printed in that publication.

- Be sure to reference your connection to kidney disease.
- Make sure you include your name and hometown in the letter.
- These should be persuasive and include detail on your topic.

Op-Eds

- They do not need to be in response to something published in the paper. They can be as long as 750 words.

- Begin with something compelling and current to grab the reader's attention.
- State your problem, and a solution to it.
- Share your kidney disease story.
- Finish with a call to action, like "Call your Senator" or "To support patients sign up at [voices.kidney.org!](https://www.kidney.org/voices)"

ADVOCACY RESOURCES

NKF's website for messaging your legislators and signing up as an advocate:

voices.kidney.org

NKF's advocacy resources webpage, hosting fact sheets, and advocacy guides (like this one):

kidney.org/advocacy/resources

NKF's social media and video advocacy guide:

voices.kidney.org/advocacy-social-media-toolkit

NKF's "Advocacy in Action" blog to stay up to date on changes to policy and new initiatives:

kidney.org/advocacy-action

Find out who your legislator is:

voices.kidney.org/find-your-legislator/

Research legislation through the Library of Congress:

congress.gov/

Locate your federal legislator's webpages:

house.gov or senate.gov

The Town Hall Project, to find out about upcoming town hall events held by your legislators:

townhallproject.com/

Find out more kidney disease facts:

kidney.org/news/newsroom/factsheets/KidneyDiseaseBasics

Learn about state laws pertaining to leave and tax credits/deductions for living donors:

kidney.org/transplantation/ld_tax_ded_leave

Report back to NKF about your meetings:

NKFadvocacy@kidney.org

Locate your local NKF office to contact them:

kidney.org/offices

View our complete legislative and policy agenda:

kidney.org/advocacy

COMMUNITY ENGAGEMENT

NKF needs people of all ages and interests to volunteer.

How much time you give is up to you. Contact your local office to learn about volunteer opportunities in your area.

Community engagement provides a presence and greater representation around kidney-related issues, increases awareness, and ensures that legislators, researchers, media, and the public hear directly from those affected by kidney disease. Beyond writing and speaking to local legislators and the media, you can engage by volunteering and collaborating with NKF.

VOLUNTEER

Volunteering with NKF gives you a chance to be a part of our ongoing effort to help the 30 million Americans with kidney disease live richer, fuller lives. Help us raise awareness about early detection, risk factors, and the importance of organ donation.

NKF Kidney Walks: The nation's largest, most successful walk program to fight kidney disease, held in nearly 100 communities. These events raise awareness and help fund lifesaving programs that educate and support patients, their families, and those at risk. You can form a Walk team, raise donations, and find sponsors for your fundraising goal. Visit kidneywalk.org for more information and to find an NKF Kidney Walk near you.

NKF KEEP® Healthy: KEEP Healthy is NKF's community-based initiative designed to raise awareness about the kidney health, risk factors for kidney disease, and steps to keep kidneys healthy and reduce risk. It consists of a brief health survey, blood pressure check, body mass index (BMI) measurement, albumin/creatinine ratio (ACR) urine test, educational information, and an on-site clinician consultation.

NKF Your Kidneys and You: Designed to raise kidney health awareness among the public through trained volunteer presenters, Your Kidneys and You is a brief PowerPoint presentation with basic information about kidneys, risk factors for kidney disease, and kidney health. The goal of Your Kidneys and You is to raise awareness and encourage individuals who are, or may be, at risk for kidney disease to talk to their doctor and contact NKF for more information. To become a trained Your Kidneys and You presenter, contact your local NKF office near you to find out about upcoming training opportunities.

NKF LOCAL OFFICES

NKF REGIONAL OFFICES AND LOCAL OFFICES

NKF Serving Alabama,
Georgia, and Mississippi
Atlanta, GA
770.452.1539

NKF Serving the Alleghenies
Pittsburgh, PA
412.261.4115

NKF of Arizona
Phoenix, AZ
602.840.1644

NKF Serving the Carolinas –
North Carolina
Charlotte, NC
704.519.0020

NKF Serving the Carolinas –
South Carolina
Columbia, SC
803.799.3870

NKF of Central New York
Syracuse, NY
315.476.0311

NKF Serving Central Ohio
Columbus, OH
614.882.6184

NKF Serving Colorado and
New Mexico
Denver, CO
720.748.9991

NKF Serving Connecticut and
Western Massachusetts
Cheshire, CT
203.439.7912

NKF Serving the Dakotas
Sioux Falls, SD
605.360.4939

NKF Serving East Tennessee
Knoxville, TN
865.221.2121

NKF Serving Eastern Missouri,
Metro East, and Arkansas
St. Louis, MO
314.961.2828

NKF of Florida
Orlando, FL
407.894.7325

NKF Serving Greater Cincinnati
Cincinnati, OH
513.961.8105

NKF Serving Greater New York
New York, NY
212.889.2210

NKF of Hawaii
Honolulu, HI
808.593.1515

NKF of Illinois
Chicago, IL
312.321.1500

NKF of Indiana
Indianapolis, IN
317.722.5640

NKF Serving Iowa, & Nebraska
West Des Moines, IA
515.440.0402

NKF Serving Kentucky
Louisville, KY
502.585.5433

NKF of Louisiana
New Orleans, LA
504.861.4500

NKF of Maryland and Delaware
Lutherville, MD
410.494.8545

NKF of Michigan
Ann Arbor, MI
734.222.9800

NKF Serving the
National Capital Area
Washington, DC
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414.897.8669



CAPITOL HILL STAFF

Member of Congress (Member):

Your elected official who represents you in Congress. Congress is comprised of the House of Representatives and the Senate.

Representative: There are 435 representatives in the House of Representatives. These officials represent districts within their state. Each citizen has an official that represents the district they live in.

Senator: There are 100 senators in the U.S. Senate with each state having two senators.

Chief of Staff: Typically runs the Washington, D.C. office, manages the staff, and serves as the chief advisor to the Member of Congress.

Press Secretary/Communications Director: Manages the Member's media relations and public communications. This often includes press releases, event and floor speeches, newsletters, social networking, and responding to and tracking media inquiries.

Executive Assistant/Scheduler: Administers the Member's office and the official's schedule and travel. Scheduling often entails constituent meetings, committee meetings and hearings, district travel, receptions and special events, and press conferences. They are the gatekeeper for their office and the legislator.

Legislative Director (LD):

Supervises the legislative staff and operations of the office. The LD advises the Member on legislative activity in all areas. Frequently approves correspondence.

Legislative Assistant (LA):

Handles and advises on legislative/policy issues in a select number of issue areas for their legislator. Monitors and analyzes specific legislation and recommends action to the Member of Congress based on the Member's position. Topics are typically divided based on the Member's committee assignments and general committee breakdown of issues. Frequently meets with constituents regarding issues in their assigned area. Frequently drafts and/or edits correspondence.

Legislative Correspondent (LC):

Receives, logs, and drafts responses to all constituent-generated legislative mail. Frequently coordinates written responses to constituents with LAs and LDs. Some typically handle one or two issue areas as well.

Staff Assistant/Receptionist:

A position not to be overlooked. This person is often the first one you speak with on the phone, meet when you walk into the office or talk with regarding general requests (e.g., flags, tours, mail). They are frequently

a gatekeeper to all of the inner offices and many move up in the office at a later date. *Be one of the smart ones who develops a relationship with this staff member.*

DISTRICT STAFF

District Director: Responsible for managing all official activities outside of Washington, D.C.

Caseworker/Field Representative:

Handles personal constituent issues, "casework," with a federal agency (i.e., Social Security checks, veteran's benefits, etc.) Often coordinates district events, office hours, and meetings throughout the district. He/she serves as an in-district contact when the Member is in Washington for a legislative session.

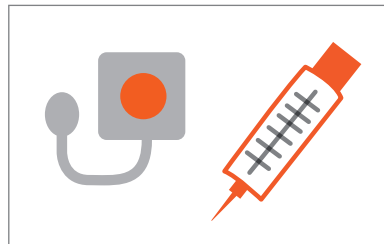


FAST FACTS

Anyone can get kidney disease at any age.



The main causes of kidney disease are high blood pressure and diabetes.



Simple blood and urine tests can be used to check for kidney disease.



1 in 3

American adults are currently at risk for developing kidney disease.



An estimated

37 million

American adults are estimated to have kidney disease.

1 in 7

has kidney disease and most don't know it.



726,000+

Americans have irreversible kidney failure and end-stage kidney disease, and require dialysis or a kidney transplant to survive.

African Americans, Hispanics, Asians Pacific Islanders, American Indians, and Seniors are at increased risk for developing kidney disease.

Medicare spends over

114 billion

annually caring for people with CKD and ESKD.





Patient
Engagement &
Advocacy
Guide



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kidney.org