

National Kidney Foundation Patient Engagement & Advocacy Guide



Dear Advocate:

Welcome to The National Kidney Foundation (NKF) Patient Engagement & Advocacy Guide.

We value your commitment to empowering and educating others about chronic kidney disease (CKD), as well as effecting change through policy and legislation. NKF Advocates write directly to Congress and to newspapers, visit Members of Congress in Washington, D.C., or District offices, and advocate through social media. You may also be active in raising awareness in your communities, lending your voice to committees or advisory panels/boards, and participating in focus groups to ensure the kidney patient story is incorporated into program, policy, and treatment-related decision making.

As the nation's leading kidney disease 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 NKF's 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 resources for contacting legislators, suggestions for engagement within your community, and statistics and other information on kidney disease. While tips, tactics, and statistics are important, your personal experiences with kidney disease are your most powerful asset. Your personal story is the most effective way to make an impact on elected officials and their staffs. In this guide you will find tips on how to deliver that story with the greatest impact.

We hope you find this guide helpful!

Thank you again for your dedication to the kidney community!

Ewodaghe Harrell, MPH
NKF Kidney Advocacy Committee

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Andrew Fullerton



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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 success as the largest national kidney patient advocacy organization is dependent on our ability to engage and mobilize people affected by kidney disease across the country. Legislators want to hear from their constituents on how policy and legislative proposals affect their lives. Having a strong, united base of advocates throughout the country brings a voice to NKF's national policy goals. However, advocacy is not only about garnering the attention of legislators and policymakers; it is also about driving greater public awareness.

We look to you, as one of NKF's partners in advocacy, 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 U.S. Expanding our reach helps us bring greater attention to kidney disease as a public health crisis. Raise the bar by pushing our communities and government 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!



PATIENT ENGAGEMENT & ADVOCACY

The NKF Patient Engagement & Advocacy Guide provides information and resources on ways you, as a kidney patient, living donor or family member, can assess, articulate, and pursue the best strategies available for advocating kidney disease awareness, prevention, and treatment. As an empowered individual, you stand 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, caregivers, and medical practitioners. The tie that binds them is their desire to make a difference for kidney patients.

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 join the top tier of NKF's grassroots advocacy network, speaking out to ensure that policy and programs support what is best for kidney patients and families.

Characteristics of an Effective Advocate:

- Leadership skills
- Passionate and can speak from the heart
- Ability to clearly articulate issues and challenges in the kidney community
- Tells unique and compelling personal stories
- Knowledge/interest in public policy process and/or policy issues
- Committed to long-term involvement
- Understands the "bigger picture"
- Desire to help fellow 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.

GETTING STARTED

HOW SHARING YOUR STORY HELPS

Sharing your story with your legislators allows them to understand the reality of kidney disease. Your story 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.

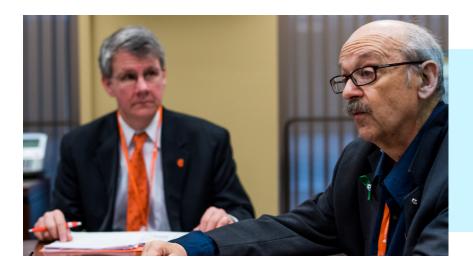
FIRST THINGS FIRST!

Before we dive deeper into top-tier advocacy, let's check to see if you have asked your friends, family, and colleagues to sign up at NKF's Advocacy Action Center to email or tweet their legislators? Have you taken action by messaging them?

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 you.
- Summarize your story. You will likely have a short time with the legislator or staff. Therefore, focus on key points of your personal experience. Discuss the challenges of living with kidney disease, but try to 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 a Republican, Democrat, or Independent. You are an advocate for 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 bill.
- Say thank you. Always thank your legislator or their staff for their time. You should let them know that you would like to serve as a resource on kidney disease issues.



Always thank your legislator or their staff for their time.

WORKING WITH LEGISLATORS

Advocacy should start well before the bill you are concerned about is introduced. A good time to start is when Members visit their districts. Set up a meeting with them at their local office. Legislators and their staff are also accessible at their Washington, D.C. offices. Consider visiting your Member of Congress if you are visiting in the nation's capital. Advocacy from the local level 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 with your own legislators.



QUICK TIPS

working with legislators

Know your legislators. Learn your Members' committee assignments, staff, where his or her specialties lie, and their professional background prior to election to office.

To be an effective voice for kidney disease patients, it helps to know where your representatives stand on CKD policy and related bills. You can find information on the NKF Advocacy webpages, and the websites of elected officials and their legislatures.

The NKF Advocacy and Policy Website

(kidney.org/advocacy) includes links to fact sheets on policy and legislation, 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.

THOMAS (congress.gov) provides legislative information from the Library of Congress. Check there 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 for kidney patients.

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

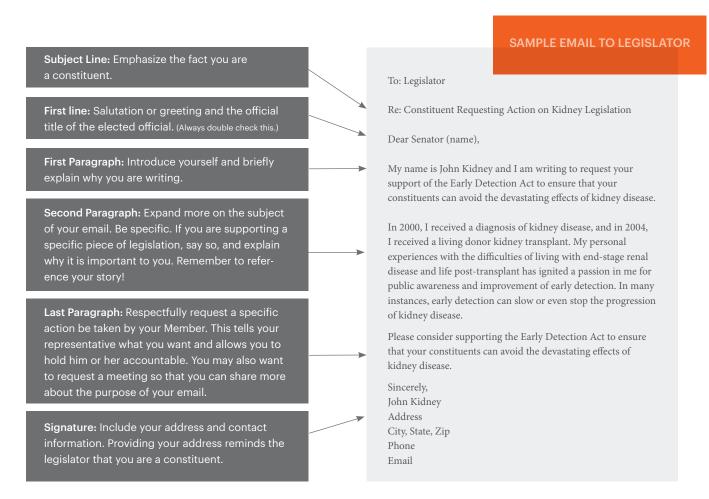
EMAIL COMMUNICATIONS

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.

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

When writing an elected official, be concise, yet informative. Confine your correspondence to a single subject and ensure there are no grammatical errors. Make sure to personalize your email; it makes an enormous difference! Here is what you will need in each section of the email:



MEETING WITH LEGISLATORS

FACE-TO-FACE MEETINGS

Another way to make your voice heard as an advocate is to request a face-to-face 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 <u>Senate.gov</u>. 77% of congressional staff believe that these meetings have a significant impact on their legislators' decisions.

House:	Senate:
majorityleader.gov/floor/#annual	senate.gov/legislative/2019_schedule.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. Request your appointment with your legislators, but you may meet with their staff first. Don't hesitate to follow up on a request. 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 congressional webpage. You should also invite local NKF staff and other people to join you.

PREPARING FOR YOUR MEETING

Visit **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. They can help you prepare for the meeting and provide 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 professionally. 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 handed them 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

March 10, 2019

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



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 30 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."] legislation that would extend Medicare coverage for immunosuppressive drugs for the life of the kidney transplant for people unable to obtain health insurance.

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 #

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 by phone

- Contact your legislator's office, sign up for their mailing list, or visit www.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.
- Be sure to mention your name and town.
- Make sure to mention you are a kidney patient, family member, living donor, or healthcare practitioner.

- Be respectful of the event and don't get pushy with the legislator or other guests.
- Be unique—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. 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. It 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 10–30 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 advocacy.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 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 #mykidneysmylife

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









QUICK TIPS

on facebook

- "Like" the Facebook pages of your legislators and local NKF office pages.
- Share content from the main NKF Facebook page, www.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 advocacy.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.
- Use #MyKidneysMyLife

QUICK TIPS

on twitter

- 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 #MyKidneysMyLife

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

Sample Facebook Post: I'm supporting kidney patients and organ donors with the National Kidney Foundation by urging @[YourREP/SEN] to support the Living Donor Protection Act (H.R. 1270) and help protect living organ donors. #MyKidneysMyLife

SHARING YOUR STORY THROUGH MEDIA

MEDIA OUTLETS

Communicate your story and spread the word.

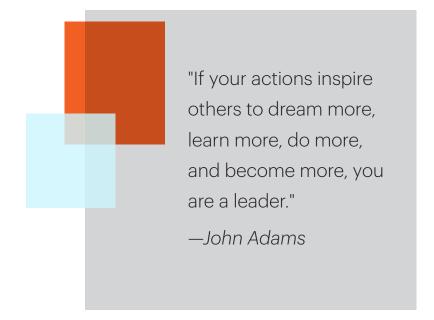
PRINT

Local newspapers and magazines are examples of print media outlets for sharing your story. Begin by contacting NKF Government Relations, which will work with Marketing and Communications to help you target publications or reporters who recently ran articles on kidney disease, or whose past coverage aligns with your message. Media outlets typically have an online component, and their websites are 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.
- Try referring to a recent story or current policy action that relates to kidney disease or upcoming NKF event.
- 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.



SHARING YOUR STORY THROUGH MEDIA

PHONE, TV, OR RADIO INTERVIEW

In-person and phone interviews are great opportunities. Find out what the reporter is seeking and 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 advocacy.kidney.org!"

ADVOCACY RESOURCES

NKF's website for messaging your legislators and signing up as an advocate: https://advocacy.kidney.org/

NKF's advocacy resources webpage, hosting fact sheets, and advocacy guides (like this one): https://www.kidney.org/advocacy/resources

NKF's social media and video advocacy guide:

https://advocacy.kidney.org/advocacy-social-media-toolkit

NKF's "Advocacy in Action" blog to stay up to date on changes to policy and new initiatives: https://nkfadvocacy.wordpress.com/

Find out who your legislator is:

https://advocacy.kidney.org/find-your-legislator/

Research legislation through the Library of Congress:

https://www.congress.gov/

Locate your federal legislator's webpages:

www.house.gov or www.senate.gov

The Town Hall Project, to find out about upcoming town hall events held by your legislators: https://townhallproject.com/

Find our more kidney disease facts:

https://www.kidney.org/news/newsroom/factsheets/KidneyDiseaseBasics

Learn about state laws pertaining to leave and tax credits/deductions for living donors: https://www.kidney.org/sites/default/files/LD Tax Ded Leave 6 23 18.pdf

Report back to NKF about your meetings:

NKFadvocacy@kidney.org

Locate your local NKF office to contact them:

https://www.kidney.org/offices

COMMUNITY ENGAGEMENT

NKF needs
people of all ages
and interests to
volunteer.

Community engagement provides a presence and greater representation in the community, 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.

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

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 202.244.7900

NKF Serving New England
Norwood, MA

NKF Serving North Texas/ West Texas

Dallas, TX 214.351.2393

781.278.0222

NKF Serving Northern California San Francisco, CA 415.543.3303

NKF Serving Northern Ohio Bay Village, OH 440.933.4909

NKF Serving the Pacific Northwest San Francisco, CA 253.201.0881

NKF Serving Philadelphia/ Delaware Valley Philadelphia, PA 215.923.8611

NKF Serving South & Central Texas Austin, TX 512.230.5655

NKF Serving Southeast Texas Houston, TX 713.360.6784

NKF Serving Southern California and Nevada Sherman Oaks, CA 818.783.8153

NKF Serving Upstate New York Rochester, NY 585.598.3963

NKF of Utah Provo, UT 801.226.5111

NKF Serving Virginia Richmond, VA 804.288.8342

NKF of West Tennessee Memphis, TN 901.683.6185

NKF Serving Western Missouri, Kansas and Oklahoma Overland Park, KS 913.262.1551

NKF Wisconsin West Allis, WI 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.

A simple blood and urine test can be used to check for kidney disease.







1 in 3

American adults are currently at risk for developing kidney disease.



1 in 7

has kidney disease and most don't know it.



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



An estimated

30 million

American adults are estimated to have kidney disease.



700,000+

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

Medicare spends nearly

100 billion

annually caring for people with CKD and ESRD.



Patient Engagement & Advocacy Guide



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30 East 33rd Street New York, NY 10016 kidney.org