



Making the Most of Your Congressional Meetings

July 2022

Agenda

- Why we meet
- Scheduling and preparation
- Advocates are storytellers
- Our agenda
- Best practices
- Follow up! Follow up! Follow up!
- Q&A and adjourn

101: Why Meet with Lawmakers?

01

Why are these meetings important?

Show the face of their constituency while legislators are “home”



02

Who are we focusing on?

Build relationships with key lawmakers and their staff who focus on issues related to kidney disease

03

Why them?

We need lawmakers to co-sponsor bills and help advance policies that benefit the kidney patient community

Figure 7 | Influence of Advocacy Strategies to Washington Office on Undecided Member

If your Member/Senator has not already arrived at a firm decision on an issue, how much influence might the following advocacy strategies directed to the *Washington office* have on his/her decision?

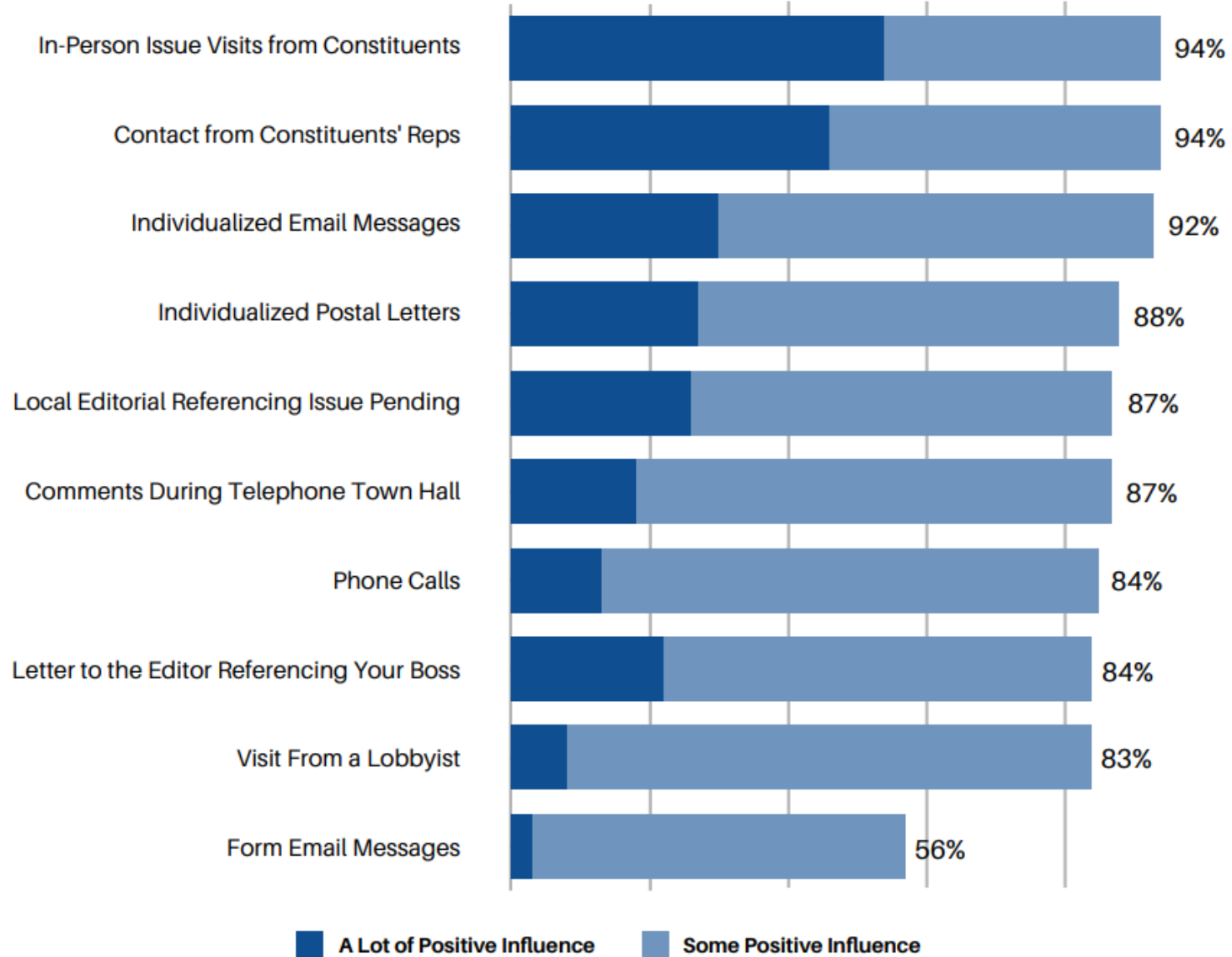
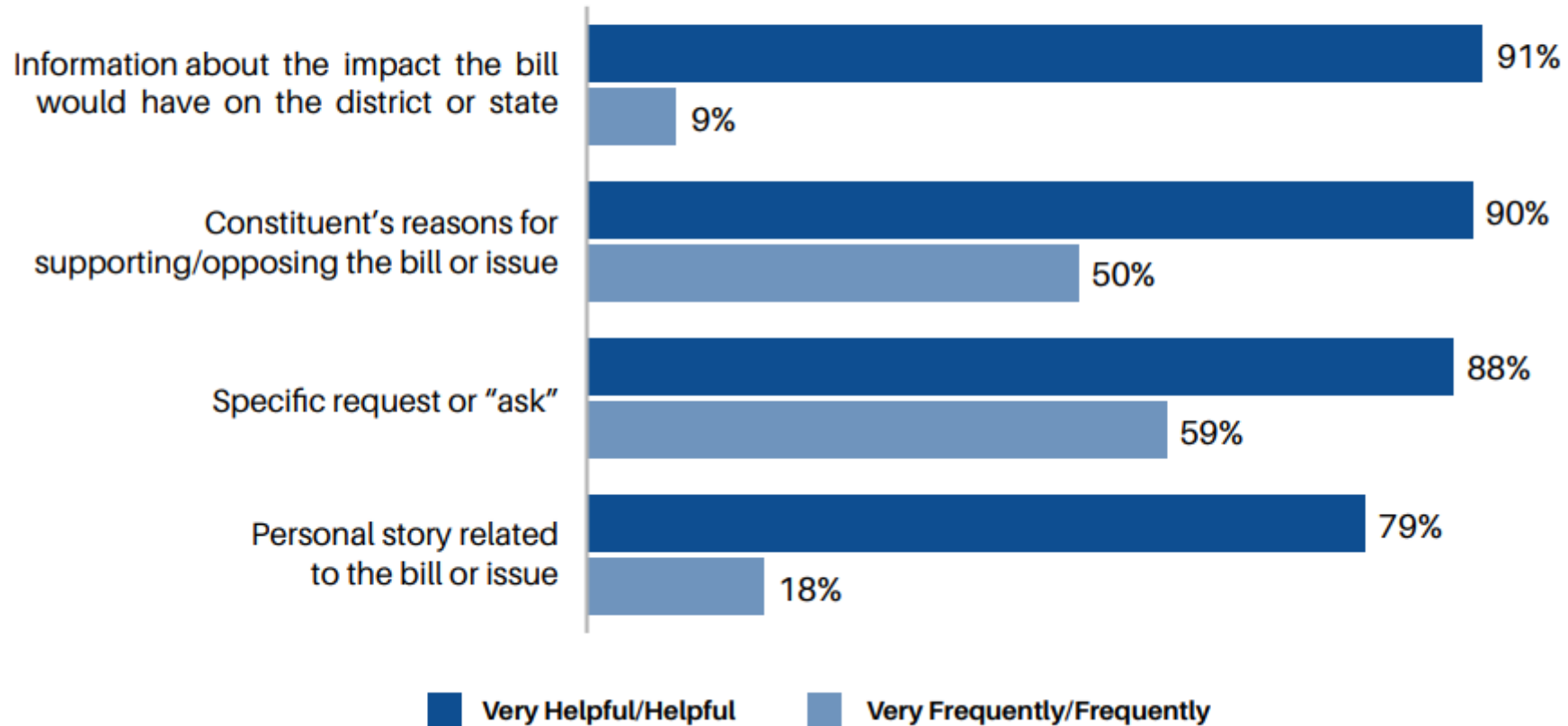


Figure 6 | Frequency versus Helpfulness of Specific Information in Constituent Advocacy

**How helpful is it for messages from constituents to include the following?
How frequently do messages from constituents include the following?**



Getting on the agenda (part one)

Emailing the office

- If you have never met with the office before, email the office scheduler (we'll help!).
- If you have met them before, email the staff member you have a relationship with, typically the Healthcare Legislative Assistant

Who to meet with

- The Health Legislative Assistant if requesting a DC meeting (ideal if the meeting is virtual)
- The District Director or Healthcare Caseworker if a district office meeting

Getting on the agenda (part two)

What to include in your request

- Date, time and location of the meeting (including links if virtual)
- Who is attending and their contact information
- Organization represented (NKF)
- Issues for discussion and supporting documents

Request a virtual meeting

- With COVID-19 being an ongoing issue for kidney patients, it's understood that you may want to request a virtual meeting. If you feel comfortable meeting in person, say so in your request.



Failing to prepare is preparing to fail

- Review fact sheets, one pagers, and talking points, and make sure you can explain the bills to a family member or friend.
- Practice telling your story! Write down the key points and practice explaining it to someone in 3-5 minutes.
- Review our steps to a successful meeting.
- Remember that staffers do this all the time and are here to help facilitate a productive meeting. They have definitely had people get tongue tied before.

Steps for a successful meeting

01

INTRODUCTIONS

Introduce yourself, thank the staffer for the meeting, and remind them of the topic.

“Hello, my name is Anita, and I am an advocate with the National Kidney Foundation. I also have Chronic Kidney Disease. Thank you for meeting with me. I am here today to talk about policies that would help kidney patients. Specifically, I am asking you to support the Living Donor Protection Act and the Home Dialysis Bill.”



02

TELL YOUR STORY

Share your personal story in about 3-5 minutes. Make sure you close with the one thing you want them to take away from your story, and then transition to asking for their support for the Home Dialysis bill and Living Donor Protection Act.

Steps for a successful meeting

03

MAKE DIRECT LEGISLATIVE ASKS

“Now that I’ve told you my personal story, I’d like the Congressperson to please cosponsor the Living Donor Protection Act and the Home Dialysis Bill. These policies will help get more patients a kidney transplant and help more patients access home dialysis.”

04

ANY QUESTIONS?

Let the staffer absorb what you’ve said and give them time to ask any questions. If they ask a question that you don’t know the answer to, that’s OK! Just tell them you don’t know and that you’ll work with NKF staff to follow up and get an answer.

05

THANK YOU & FOLLOW UP

Wrap up by thanking the staffer for their time and promising to follow up soon. Let NKF staff know how your meeting went!

Advocates are storytellers

- Put a human face on kidney disease and give your fellow patients a voice
- Sharing your challenges and successes makes these issues more real and immediate to lawmakers
- Always consider: What is the purpose of your story?
- Do you want to elicit an emotional response? Prompt a discussion about facts?
- Know your audience before telling your story



Components of a good story

- Relatability
- Weave together facts and emotion
- Know your audience
- Transition to the solution
- Words matter
- Brevity, always





What does a good story sound like?

Relatability

“My mother was a short lady with bright brown eyes. I could tell something was wrong that day because her eyes were sad and she wouldn’t look at me.”

Weave together facts and emotion

“If my mother had assistance dialyzing in the home, she wouldn’t have had to travel so long and so far and would’ve been healthier longer.”

Know your audience

“My mother was only on dialysis for a year before she died. I know that is not as long as some people but I still got to see how difficult it is.”

Transition to the solution

“That’s why I’m asking you to please support our bill to improve access to home dialysis. It would have helped my mother live a longer, healthier life.”

Use the Right Words

“My mother was on dialysis, which is the process of filtering the blood of patients in kidney failure.”

117th Congress

NKF Legislative Priorities

01

REMOVE BARRIERS

to living donation and organ transplantation
to make transplants more available

02

EXPAND ACCESS

to home dialysis to ensure all patients are
given the chance to succeed on this
modality if they choose.

03

INCREASE FUNDING

for kidney disease awareness, early
detection and early treatment, and research.



PRIORITY ONE

Increasing Transplantation

1 /

Over 106,000 Americans are on the transplant wait-list.

2 /

Only 24,699 received a kidney transplant last year.

3 /

Every day, 12 people die waiting for their transplant.

4 /

Patients of color face additional barriers to receiving a transplant, and wait on average a year longer than white patients to receive a transplant.

5 /

Congress must prioritize making more organs available for transplant by supporting living donation and ending insurance discrimination against living donors.

PRIORITY ONE

The Living Donor Protection Act (S 377/HR 1255)

- This bipartisan, non-controversial bill prohibits discrimination against living donors in the provision and rates of life insurance, disability insurance, and long-term care insurance.
- Also codifies Department of Labor directive to include organ donation as an eligible serious medical condition under the Family Medical Leave Act (FMLA).
- The American Council of Life Insurers supports this bill.
- It is sponsored in the Senate by Senators Kirsten Gillibrand (D-NY) and Tom Cotton (R-AR), and in the House by Congressman Jerry Nadler (D-NY) and Congresswoman Jaime Herrera Beutler (R-WA).
- **ASK: Please co-sponsor the Living Donor Protection Act and help us get an Energy and Commerce committee hearing on the bill this year.**



PRIORITY TWO

Expanding Access to Home Dialysis

1 /

Over 85% of the 550,000 Americans on dialysis travel to a facility multiple times per week for several hours at a time.

2 /

During COVID, these patients have had some of the highest rates of infection, hospitalization, and mortality due to travelling outside the home and sitting in a congregate care facility.

3 /

Home dialysis is used heavily in other countries, yet here only 12% of patients participate in home hemodialysis or peritoneal dialysis.

4 /

NKF asks Congress to prioritize removing barriers to home dialysis and ensuring all patients are afforded the opportunity to succeed on this modality.

PRIORITY TWO

Improving Access to Home Dialysis Act of 2021 (HR 5426)

- This bill is sponsored in the House by Reps. Bobby Rush (IL) and Jason Smith (MO).
- This bill adds coverage for professional staff to assist patients in performing dialysis at home.
- It also includes a study on racial disparities in home dialysis and calls for a new dialysis patient quality of life metric.
- This bill has not been introduced in the Senate yet. Please ask your Senators to consider being an original sponsor.
- **ASK: Please cosponsor this bill.**



PRIORITY THREE

Increase Funding for Kidney Disease Awareness and Research

1 /

More than 37 million Americans have CKD, including nearly 750,000 with irreversible kidney failure.

2 /

Another 80 million Americans are at risk for developing kidney disease from hypertension, diabetes, and other risk factors.

3 /

90% of those with CKD have not been diagnosed.

4 /

Medicare currently spends approximately 25% of its budget treating kidney disease, yet federal funding for kidney disease research has lagged in recent years.

5 /

If we do not address kidney disease upstream and slow or stop the progression to kidney failure, we could have over one million patients in kidney failure by 2030.

6 /

The cost of treating these patients could bankrupt the Medicare Trust Fund.

PRIORITY THREE

Appropriations Request / Thank You!

CENTERS FOR DISEASE CONTROL (CDC) & PREVENTION CHRONIC KIDNEY DISEASE INITIATIVE

- Increase funding to the CKD Initiative at CDC, which focuses on a comprehensive public health strategy to address CKD.

NATIONAL INSTITUTES OF HEALTH (NIH)

- Increase funding to the National Institutes of Diabetes, Digestive, and Kidney Diseases at a level commensurate with increases to other Institutes to address historical underfunding of NIDDK.
- We appreciate the House funding these priorities and hope the conference committee will do the same.

Do This!



Be positive

Everyone should leave the meeting on an upbeat note.



Keep it simple

Use phrases like “kidney failure,” rather than “end stage renal disease” or “ESRD.”



Brief and focused

Explain how the lawmaker can positively impact the patients they represent.

Steering Clear

01

Talk Politics or Other Non-Kidney Topics

If the discussion turns partisan or gets off topic, emphasize that you're here to talk about the needs of kidney patients.

02

Make things up or “wing it”

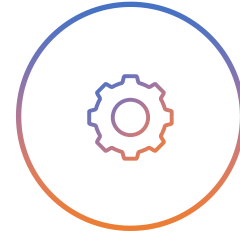
If you don't know the answer to a question, just say so. Share the question with NKF staff after the meeting and we'll work with you to follow up (or have your back).

After your meeting



Say Thank You!

- Send a thank you note by email
- Send copies of PDFs NKF staff have provided
- Send a copy of the photo you took with them



Nurture the Relationship

Stay connected to ensure their support for future and ongoing kidney patient policies



Get Social

Post your photo with a thank you note on Twitter and include @nkf_advocacy and #MyKidneyVoice

Let Us Know How it Went!



Who to report to?

Lauren Drew and
Matthew Fitting



Get a photo!

During your meeting,
ask for a photo /
screenshot!



What to Report

- Who did you meet?
- Their reactions?
- Willing to support our policy?
- What questions did they have?

Q & A

Thank you for your advocacy!

Contact information:

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Matthew Fitting

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VOICES 

FOR KIDNEY HEALTH TM

National Kidney Foundation