



Kidney Action Summit 2022

Ambassador Training

April 28, 2022

Training Agenda

- Introduction (Holly) – **5 minutes**
- Advocacy 101 Presentation (TOGA) – **15 minutes**
- Advocacy Throughout the Year – **5 minutes**
- About the Web Portal (Kate) – **10 minutes**
- Social Media (Kristina) – **10 minutes**
- How to Tell Your Story (Tamara) – **15 minutes**
- Q&A (Everyone) – **5 minutes**
- Breakout rooms – **25 minutes**
- Additional time for questions (optional) – **30 minutes**

What we will cover

- Quick Background on Congress and the Legislative Process
- Explanation of Advocacy
- Legislative Issues
- Format of Meeting

Quick Background on Congress & Legislative Process

- There are two chambers in the U.S. Congress:
 - House of Representatives
 - Senate
- For enactment of Legislation:
 - Both chambers must pass the legislation.
 - The legislation goes to a conference committee to work out differences and create a new bill.
 - The new bill must be passed by both chambers before going to the president for signing.

Congressional profile, 117th congress

United States House of Representatives

- 221 Democrats / 211 Republicans / 3 Vacancies

Leadership

- Speaker of the House: Nancy Pelosi (D-CA)
- Majority Leader: Steny Hoyer (D-MD)
- Majority Whip: Jim Clyburn, (D-SC)
- Minority Leader: Kevin McCarthy (R-CA)
- Minority Whip: Steve Scalise (R-LA)

Congressional profile, 117th congress

United States Senate

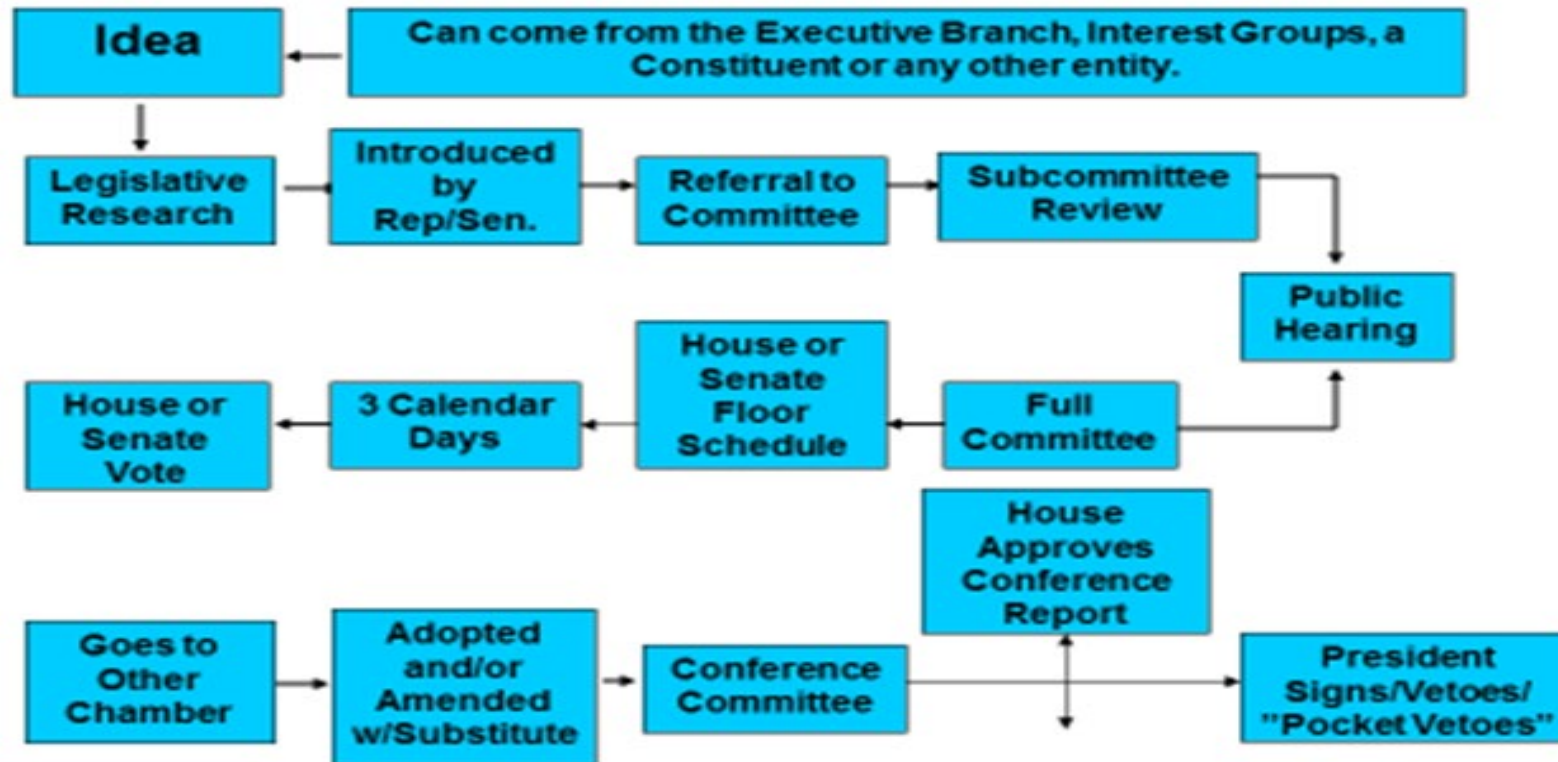
- Senate: 48 Democrats / 2 Independents who Caucus with the Democrats / 50 Republicans
 - Vice President Kamala Harris Breaks Tie

Leadership

- Majority Leader: Chuck Schumer (D-NY)
- Majority Whip: Dick Durbin (D-IL)

- Minority Leader: Mitch McConnell (R-KY)
- Minority Whip: John Thune (R-SD)

Legislative Process – In Theory



Legislative Process – In The Real World

There are many opportunities to influence the process.



What is Advocacy?

- Organized activity with the purpose of influencing the formulation of public policy.
- Communications and activities that educate Congress, policy makers and the public.
- Communications and activities that build public support.

What is Advocacy?

- Influencing people, policy, structures and systems;
- Lobbying, mobilizing, educating and networking;
- Alone/with a group of people/with coalition of organizations;
- Aimed at immediate results or a long term objective;
- Holds those in power accountable;
- Empowers individuals to speak up for themselves.

Why Advocate?

- Develop individuals as agents of change.
- Generate more resources for kidney patients;.
- Change power structures and systems to enhance support for those with chronic kidney disease and those on dialysis.
- Representative democracy relies on the bond between citizens and their legislators.

Why Should You Advocate?

- Decisions will be made regardless of who participates in the process.
- Your personal experience and expertise can enhance policy decisions made at the local, state, and national levels.
- Legislators make their decisions based on your experiences. They need to hear from you.
- Affect policy outcomes--enact needed changes in the law that improve kidney health.

Thank you for your advocacy!

Goals of Your Meeting on May 4th

- Goal 1: To introduce yourself and the issue of kidney disease to your elected officials.
- Goal 2: To give the congressional staffer the opportunity to hear **your story** - the constituent's story - and understand how kidney disease impacts a person's life.
- Goal 3: Build a relationship between with the congressional staffer.

Format of Meeting

The meeting format is as follows:

- 1) AKF Staffer will introduce herself/himself
- 2) Give background on the American Kidney Fund
- 3) AKF Staffer will introduce Ambassador
- 4) Ambassador tells their story**
- 5) AKF staff will quickly discuss two bills:
 - A. Living Donor Protection Act
 - B. CARE for All Kidneys Act
- 6) AKF staffer will ask congressional office to sponsor these bills
- 7) Thank the staff for the meeting, say goodbye and end the Zoom meeting.

AKF's Virtual Kidney Action Summit Legislation

- S. 377/H.R. 1255, the *Living Donor Protection Act*
 - Introduced in the House and Senate – Request cosponsorship
- H.R. 3893, the *CARE (Coordination, Accountability, Research and Equity) for All Kidneys Act*
 - Only introduced in the House of Representatives – Request cosponsorship
 - Not introduced in the Senate – Request introduction

Legislative Issues – Issue 1

S. 377/H.R. 1255, the Living Donor Protection Act

- Prohibits insurers from declining coverage, limiting coverage or charging higher premiums to living organ donors under any life insurance, disability insurance or long-term care insurance policy
- Prohibits insurers from precluding a person from donating all or part of an organ as a condition of receiving a life insurance, disability insurance or long-term care insurance policy
- Prohibits insurers from considering the status of a person as a living organ donor in determining the premium rate for insurance
- Codifies an opinion letter from the Department of Labor that states FMLA includes organ donation surgery as a qualifying medical condition that would allow living donors to take the leave afforded to others under FMLA
- Requires the Department of Health and Human Services to update their website, brochures and other media regarding live donation and access to insurance for living donors

Script – First-person talking points

1st Issue – Living Donor Protection Act

AKF Staffer:

- The first issue I would like to discuss is the Living Donor Protection Act. We are asking for your support of **H.R. 1255/S. 377, the Living Donor Protection Act** – introduced by Cong. Nadler (D-NY) and Cong. Jaime Herrera Beutler (R-WA), and Sen. Gillibrand (D-NY) and Sen. Cotton (R-AR).
- A living donor is someone who is still alive and donates an organ so someone else can live or live more fully.
- This bill protects living donors by ensuring they will have access to a life insurance policy, a disability insurance policy, and a long-term care insurance policy. It prohibits life, disability and long-term care insurers from denying a plan or charging a higher premium to a living donor

Script – First-person talking points

Continued--1st Issue – Living Donor Protection Act,.

AKF Staffer:

- This legislation also guarantees job-protected leave for living donors under the Family and Medical Leave Act.
- The Family Medical Leave Act (FMLA) provides unpaid time off from work.
- Finally, the bill would require the HHS to update its website so living donors will know that they can get life, disability, or long-term care insurance.
- Request to Representative and Senator– Will you cosponsor?
- If they already cosponsored*, please say thank you.

*We will make sure you have access to this information

Legislative Issues – Issue 2

This bill is only in the House of Representatives

CARE for All Kidneys Act of 2021 (H.R. 3893)

- The bill requires a study on why kidney disease disproportionately impacts underserved and rural communities and communities of color.
- The study would focus on geographic location, socio-economic status, environment, occupation, race and ethnicity to understand why the kidney disease of people in certain groups progress to kidney failure, when other groups discover their kidney disease early and kidney failure is avoided.
- After the study is completed, there will be a national action plan. Primary care providers (PCPs) would be educated on kidney disease because kidney screenings are still not included in yearly physical examinations.
- There will be public awareness campaigns through the CDC to educate at-risk communities, so they request a kidney screening.
- The bill also increases the number of nephrologists in underserved communities by including them in the National Health Service Corps, which is a federal program that places physicians in underserved communities.

Script – First-person talking points

This bill is only in the House of Representatives

2nd issue: CARE for All Kidneys Act of 2021 (H.R. 3893)

- The 2nd bill we want to talk about is the CARE for ALL Kidneys Act, which was introduced by Rep. Lisa Blunt Rochester (D-DE) and Rep. Brad Wenstrup (R-OH) in June 2021.
- The bill requires a study on why kidney disease disproportionately impacts underserved and rural communities and communities of color.
- The study would focus on geographic location, socio-economic status, environment, occupation, race and ethnicity to understand why the kidney disease of people in certain groups progresses to kidney failure, while other groups discover their kidney disease early and kidney failure can be avoided.
- After the study is completed, there will be a national action plan. Primary care providers (PCPs) would be educated on kidney disease because kidney screenings are still not included in yearly physical examinations.

Script – First-person talking points

This bill is only in the House of Representatives

Continued--2nd issue: CARE for All Kidneys Act of 2021 (H.R. 3893).

- There will be public awareness campaigns through the CDC to educate at-risk communities, so they can know to request a kidney screening.
- The bill also increases the number of nephrologists in underserved communities by including them in the National Health Service Corps, which is a federal program that places physicians in underserved communities.
- Request to Representative: Will you cosponsor?
- Request to Senator: Would you be interested in sponsoring this bill in the Senate?

Logistics

- AKF staff member pairings
- Day-of meeting logistics:
 - Type of meeting: over Zoom – even if staffer doesn't turn on video, please use it if possible!
 - If you are meeting with your Member of Congress, we will reach out to you separately to let you know
- Landing page with materials
- Office hours with Ben will be held on Friday, 12:30-3 EST or by schedule
- Web portal with schedules
 - Schedules will be emailed on Friday
 - Even after you receive your schedule, it is possible some of your meetings will change
- Day-of contact: with any issues, text or call Kate at **(425) 785-8671** or email at ktremont@kidneyfund.org
 - We will email this info out on the morning of 5/4 as well

Advocate Further with AKF

- In-District Meetings
- Social Media
- State Advocacy
- Action Alerts
- Ambassador Monthly Zoom Briefings
- Connect With Your Elected Officials
- Storyvine Video

Ladder of Engagement

- Follow AKF on Facebook and Twitter, Join AKF Ambassadors Facebook group
- Connect with Elected Officials
- Share AKF Social Media Posts and Comment On Them
- Do Action Alerts
- Become A Kidney Health Coach
- Participate In An In-District Meeting
- Submit Testimony for State Legislation
- Meet with Elected Officials