



ANNA

**Health Policy
HANDBOOK**

16th Edition

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Foreword

Nurses are the largest group of health care professionals and must take a major role in shaping the future of health care delivery in the United States through active participation in the development of health care policy. Increasingly, health policy is being made by elected and appointed officials who are not particularly knowledgeable about health care and it is crucial for nurses to educate and influence policy makers. Who better to educate than a nurse?

So much of nurses' professional lives are and will continue to be affected by legislation. As nephrology nurses, professional practice and policy interests are inseparable. We must not underestimate our strength and influence on the health policy process. Nurses need to be vigilant in protecting both patients and nursing practice by engaging in health policy development. It is our responsibility as patient advocates to be active advocates! We hope this handbook will be a valuable resource as you expand your health policy knowledge and promote action.

The American Nephrology Nurses Association (ANNA) has a history as a leader in the development of End Stage Kidney Disease (ESKD) health care policy. The purpose of this handbook is to provide ANNA Chapter Officers, Health Policy Representatives, and ANNA members with materials to promote political action in their chapter/state. Education of ANNA members, as well as effective networking with other local organizations, is essential to developing a strong voice that will be heard both locally and in Washington.

The information and resources presented in this handbook are provided to help ANNA members understand how a nurse can advocate for their patients and fellow nurses. The topics include:

- Learn about the many **resources available** on ANNA's Website and ANNA Connected.
- How to **monitor legislative and regulatory activities**:
 - Impacting nephrology nursing.
 - Affecting patients with Chronic Kidney Disease (CKD).
 - Issues regarding the ESKD program of Medicare.
- How you can monitor state legislative and regulatory activity that will impact the care of patients with CKD.

Happy Advocating!

The 2020-21 ANNA Health Policy Committee

Chairperson: Donna Bednarski, MSN, RN, ANP-BC, CNN, CNP

Chair Designate: Deborah Degree, BSN, RN

Molly Cahill, MSN, NP-C, APRN, BC, CNN, FNKF

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Donna Painter, MS, RN, CNN

Paula Richards, MS, RN, CNN

Teresa Villaran, MS, MSN, CNE, CNN, CCRN

Janet Betts, National Office Staff Liaison

Key Terms

There are key terms and concepts used in government when discussing health policy on any level.

Although **advocacy** and **policy** are closely intertwined, those terms have distinctly different meanings.

Advocacy is the process of actively supporting a cause by speaking or writing in favor of or defending or interceding on behalf of a person or group. Advocacy may include actions such as imparting information, providing and using tools for self-empowerment, or connecting with elected officials.

Policy is a plan or course of action, as of a government, political entity, or business, which is intended to influence or determine decisions or actions.

Understanding the difference between **legislation** and **regulation** is also crucial:

Legislation is a law passed by a legislative body.

Regulation is a set of rules or guidelines issued by an executive body such as government agencies or regulatory boards in compliance with the law.

Other terms to understand:

Appropriations refers to money that is set aside for a specific and particular purpose or purposes. A company or a government appropriates funds for the necessities of its business operations. **Appropriations** for the U.S. federal government are decided by Congress through various committees.

A **caucus** is an informal group composed of legislators who have shared concerns or interests. e.g. "a member of the Congressional Black Caucus". There are numerous caucuses including a Congressional Kidney Caucus.

A **constituent** is a citizen who is represented in a **government** by officials for whom he or she votes.

See other commonly used terms in government: [senate.gov/reference/glossary.htm](https://www.senate.gov/reference/glossary.htm)

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ANNA Structure and Organization

A. Federal Health Policy Consultants

(1) **The District Policy Group at Faegre Drinker, Biddle & Reath, LLP (Faegre Drinker).** To assist ANNA in health policy initiatives and move federal initiatives forward, Faegre Drinker have been retained and offer a broad array of government relations experience. They have a particular expertise and focus on nonprofit health professional and advocacy organizations.

The Faegre Drinker team is composed of government relations professionals who have extensive experience and can advance ANNA's interests before the legislative and executive branches of government at the federal, state, and municipal levels. Faegre Drinker can use this experience to assist ANNA in advancing their public policy and advocacy agendas.

ANNA's federal health policy consultants – principally Jim Twaddell, provide ANNA with guidance on the Association's immediate and long-term federal legislative and regulatory objectives. Faegre Drinker representation of ANNA includes the following activities:

- Providing strategic counsel and support on ANNA priority matters, including helping to identify opportunities for advancement of health policy agenda.
- Monitoring and making recommendations regarding the submission of comments to Congress and federal agencies, and drafting and submitting comments.
- Monitoring Federal Register Notices, Federal nomination opportunities, and information regarding Congressional hearings, briefings, and other events on topics of interest to ANNA.
- Reviewing legislation and proposed regulations, providing analysis, and making recommendations on ANNA's positions and actions.
- Reviewing and commenting on draft documents, sign-on letters, and other materials;
- Representing ANNA on Capitol Hill and before agencies in meetings.
- Drafting and updating legislative fact sheets and action alerts, as well as the legislative tracking chart.
- Working with ANNA's representative to Kidney Care Partners, The Alliance for Home Dialysis, and representing ANNA before the Nursing Community Coalition.
- Attending and reporting back on Medicare Payment Advisory Commission meetings.
- Drafting and circulating weekly Capitol Hill Updates.
- Providing an article on a health policy issue for the bimonthly ANNA Update publication.

The District Policy Group
at *Faegre Drinker, Biddle & Reath, LLP*

districtpolicygroup.com

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(2) Consultant to Kidney Care Partners

ANNA supports a consultant to Kidney Care Partners to represent ANNA on Kidney Care Partners (KCP). KCP is a coalition of more than 30 organizations comprised of patient advocates, dialysis professionals, care providers, researchers, and manufacturers dedicated to working together to improve quality of care for individuals living with kidney diseases. This consultant represents the positions of ANNA and nephrology nursing as defined in ANNA's health policy agenda and position statements in discussions with KCP on matters of legislation, federal government programs, and health policy that affect access to, and care of, individuals with CKD. The consultant assists and advises ANNA in allocating its advocacy resources to respond to threats and opportunities in the federal legislative and regulatory environment and reports to the designated Board of Directors (BOD) Liaison and the ANNA National President. More information on KCP can be found on their website at: kidneycarepartners.com

(3) Consultant to the Alliance For Home Dialysis

ANNA also supports a consultant to the Alliance for Home Dialysis (AHD). The Alliance is a coalition of dialysis stakeholders representing patients, clinicians, providers and industry who have come together to promote activities and policies that facilitate treatment choice in dialysis care while addressing systemic barriers limiting access for patients and their families to the many benefits of home dialysis. Like the consultant to KCP, the consultant to AHD represents the positions of ANNA and nephrology nursing as defined in ANNA's health policy agenda and position statements. More information can be found on their website at: homedialysisalliance.org

B. Health Policy Committee

ANNA supports a national committee to monitor, identify, and address federal legislative and regulatory activities that could impact general nursing practice, nephrology nursing practice, and individuals affected by kidney disease. This committee understands, upholds, and supports the mission, purpose, objectives, policies, procedures, and strategic plan of ANNA and serves as a resource for activities at the state and local level. It also coordinates educational activities and oversees development of materials to educate individuals involved in health policy decision-making about ANNA and CKD.

C. Chapter Health Policy Representatives

Chapter Health Policy Representatives serve as officers in ANNA's 75+ chapters across the US. They monitor state legislative and regulatory activity that would impact general nursing practice, nephrology nursing practice, and individuals affected by kidney disease, promote the members' understanding of issues affecting their practice and encourages member involvement at all levels. The ANNA Chapter Support Team (ACST) is a national committee that provides support and resources to ANNA chapter officers, including Chapter Health Policy Representatives.

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ANNA Positions and Priorities

1. Health Policy Agenda

Updated annually, ANNA identifies health policy priorities that impact nephrology nursing and the care of the patient with kidney disease. [ANNA Health Policy Agenda](#)

2. Health Policy Statement

Represents ANNA's viewpoint on major health policy issues relevant to the treatment of people with kidney disease and the practice of professional nephrology nursing. This document serves to give ANNA direction as legislative and regulatory issues arise at the local, state, and national levels. [ANNA Health Policy Statement](#)

3. State Health Policy Priorities

ANNA supports action impacting the care of CKD population and nephrology nursing practice on the state level. The document identifies priorities at the state level. [ANNA State Health Policy Priorities](#)

4. Position Statements

ANNA position statements identify where ANNA stands on various positions identified as important to nephrology nursing. All position statements are reviewed by the Board of Directors biennially - half the first year of the review cycle and half the second year of the review cycle. Issues may include, but are not limited to, topics pertaining to overall nursing practice, nursing practice specific to nephrology, and the care of persons with kidney disease. If a member or group of members believes that ANNA should take a position on a matter they believe is important, a policy has been developed to identify the steps to position statement development.

A. Nursing

1. [Patient and Family Engagement](#)
2. [Nondiscrimination in Educational Programs](#)
3. [Delegation of Nursing Care Activities](#)
4. [Nurse Staffing Model](#)
5. [Cultural Diversity](#)
6. [Nurse Licensure Compact](#)

B. Nephrology Nursing

1. [The Role of the Registered Nurse in Nephrology](#)
2. [Advanced Practice in Nephrology Nursing](#)
3. [Autonomy of the Nephrology Nursing Certification Commission \(NNCC\)](#)
4. [Certification in Nephrology Nursing](#)
5. [Chronic Kidney Disease](#)

6. [Vascular Access for Hemodialysis](#)
7. [Nephrology Nurse's Role in Palliative and End-of-Life Care](#)

C. Health Policy Background

1. [ANNA Health Policy Agenda](#)
2. [ANNA Health Policy Statement](#)
3. [ANNA State Health Policy Priorities](#)
4. [Financial Incentives for Organ Donation](#)

D. Joint Positions

1. [ANNA, ASN, and RPA Joint Position Paper on Collaboration Between Nephrologists and Advanced Practice Nurses](#)
2. [Joint Position Statement of the American Nephrology Nurses Association \(ANNA\) and the National Association of Nephrology Technicians/Technologists \(NANT\) on Dialysis Technicians/Technologists](#)

3

ANNA Federal Health Policy

Federal Government Organization

In dealing with federal health policy, it is helpful to understand the government organization. In a system of checks and balances, the Constitution of the United States divides the federal government into three branches to make sure no individual or group will have too much power.

1. The Executive Branch includes:

- *President*
- *Vice President*
- *Cabinet*

The **Executive Branch** carries out the laws and includes more of the regulatory agencies. Their role is to implement and enforce certain laws. The regulatory agencies important to the care of kidney disease patients include:

- **United States Department of Health & Human Services (HHS)**, at [hhs.gov](https://www.hhs.gov), also known as the Health Department, is a cabinet-level department of the U.S. federal government with the goal of protecting the health of all Americans and providing essential human services.
- **Centers for Medicare & Medicaid Services (CMS)** at [cms.gov](https://www.cms.gov) is part of the Department of Health and Human Services (HHS). CMS is responsible for many aspects of ESKD that affect both nurses and patients. It is important to note that many but not all documents have replaced the word renal with the word kidney. CMS continues to use End Stage Renal Disease (ESRD) as ESKD is not reflected in billing at this time.
- **Food and Drug Administration (FDA)** at [fda.gov](https://www.fda.gov) is an agency within the U.S. Department of Health and Human Services. FDA is responsible for protecting public health by assuring the safety, effectiveness, and security of human and veterinary drugs, vaccines and other biological products, and medical devices
- **Drug Enforcement Administration (DEA)** at [dea.gov](https://www.dea.gov) is a federal law enforcement agency responsible for enforcing controlled substance regulations in the United States.
- **Center for Disease Control and Prevention (CDC)** at [cdc.gov](https://www.cdc.gov) is responsible for controlling the introduction and spread of infectious diseases and provides consultation and assistance to other nations and international agencies to assist in improving their disease prevention and control, environmental health, and health promotion activities.
- **The Government Accountability Office (GAO)** at [gao.gov](https://www.gao.gov) often called the “congressional watchdog” is an independent, non-partisan agency that works for Congress. They examine how taxpayer dollars are spent and provides Congress and federal agencies with objective, reliable information to help the government save money and work more efficiently.
- **The Office of Management and Budget (OMB)** at [omb.gov](https://www.omb.gov) assists the President in managing the preparation of the federal budget and supervises the administration of Executive Branch agencies.

2. The Legislative Branch (Congress) makes the laws and is composed of two parts:

- **Senate** [senate.gov](https://www.senate.gov)

There are two elected Senators per state, totaling 100 Senators. A Senate term is six years and there is no limit to the number of terms an individual can serve.

- **House of Representatives** [house.gov](https://www.house.gov)

There are currently 435 elected Representatives (the actual number may change with each census count), which are divided among the 50 states in proportion to their total population. There are additional non-voting delegates who represent the District of Columbia and the territories. A Representative serves a two-year term, and there is no limit to the number of terms an individual can serve.

3. The Judicial Branch interprets the meaning of laws, applies laws to individual cases, and decides if laws violate the Constitution. It consists of the:

- **Supreme Court**
- **Other Federal Courts**

How a Bill Becomes Law

This simplistic picture is only a small part of the process. Thousands of bills are introduced each congressional session. The 116th Congress (January 3, 2019-January 3, 2021) had 16,601 bills and resolutions introduced. From that 344 (2%) were enacted into law, 714 (4%) passed resolution, only 746 (4%) got a vote with 24 considered failed legislation and 9 were vetoed bills without an override leaving 89% were without action (govtrack.us/congress/bills/statistics). There are many opportunities to impact the process of lawmaking. The first is the bill development. Anyone can draft a bill, but it needs to have a sponsor to introduce the legislation. Other avenues to make a difference:

- Before a bill is introduced, it is beneficial to obtain co-sponsors. Co-sponsors are listed along with the original sponsor on the bill's text. The greater the number of co-sponsors increases the potential for the bill to move through the process. The bill is assigned to a Committee and then assigned to a Subcommittee. If not, the bill will not move forward. It is beneficial to have some original co-sponsors serve on the committee considering the bill. Targeting elected officials who serve on the Committee / Sub-



committee considering the bill as a co-sponsor, increase the chances of the bill moving forward. Work to identify Committee members who would be willing to ask the Committee Chairman to hold a hearing and/or mark up the bill. Hearings and mark ups need to be monitored closely for potential amendments that may change the intent of the bill.

- Once assigned to the Committee/Subcommittee it is beneficial for nurses to educate Committee members about the issues of the bill.
- If a bill passes out of Committee(s), it is not guaranteed to advance to the House or Senate floor for a vote. Sometimes House and/or Senate leaders do not support the bill and opt not to schedule a full chamber vote or other matters take a higher priority. Work is then needed to reach out to House and Senate leaders to explain why the bill should be brought forward. Work can also be done with the bill's sponsor/co-sponsors to put pressure on the leadership for a full chamber vote.
- When it goes to Conference Committee, communication is critical with sponsor/co-sponsor champions in the House and Senate to be certain that the key issues in the final legislation are secured.
- Once approved, we are not done yet! It is time to send e-mails or make calls with the White House to urge the president to enact or veto the measure. You can also contact your Representatives and urge them to contact the White House to support/oppose the measure.
- Once signed into law, the focus shifts to monitoring the regulatory process to ensure the law that is enacted meets the intent of the law.

How Laws are Made

The graphic below represents a more accurate pictorial of the process of how a bill becomes law.

Click on photo to download. Photo credit: illustration by Mike Wirth and Dr. Suzanne Cooper-Guasco



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State Health Policy

State Government

Each state has variations in the operation of its government. It would be impossible to review each state individually and therefore this information is presented as a model of a state. Many states also produce their own reference manual describing the state government and legislation. For information specific to your own state, visit (*your two-letter state abbreviation*).gov (e.g. [PA.gov](#) or [FL.gov](#)). Other sources of information may include your state's government Website.

Each state has a governor, lieutenant governor and other appointed or elected officials. Most state legislatures are composed of a Senate and General Assembly or House of Representative. Senators are typically elected for four-year terms and Representatives of the House or Delegates to the Assembly for two-year terms.

Each chamber elects its own presiding officers: A President of the Senate and Speaker of the House (Assembly). Their duties include referring bills and resolutions to committees, preparing the health policy calendar, certifying the vote on bills and resolutions, and appointing chairpersons and committee members.

It is essential that you understand the organizational structure of your state since medical/nursing practice is governed by state agencies and varies throughout the country.

In addition, there is also partisan (Democrat and Republican, the major parties in the USA) leadership, except in Nebraska, which is nonpartisan, or no official political parties. The party with the majority of members in each chamber holds all the leadership positions. Some are appointed by senior leaders, and some elected by their representative party delegations. These political leaders are recognized as the spokespersons for the policy direction in their respective houses. They "drive the agenda" of their party.

Legislative sessions vary in length from state to state, with larger states typically "in session" for longer periods of time. Short sessions (3-4 months on average) are still in existence, while other states meet in lengthy sessions ranging from 6-12 months.

The number of bills introduced each session continues to increase. It is important to familiarize yourself with your specific state model and general process for passing laws/ legislation. In many instances, the state process mirrors the federal process.

Legislation approved by both chambers is sent to the governor for signature. The governor can then sign the bill into law, allow the bill to become law without his signature (according to specified procedural rules), or veto the bill. The state legislature can override the veto by 2/3 votes of both chambers. However, if the legislature adjourns prior to the signing of a bill, the bill "dies" if the governor chooses not to approve it.

Understand your State Legislature

Begin by understanding the government process and when sessions are to be held so you know when activity happens. Identify committees that may impact nursing practice and the care of CKD patients. Identify who your Representatives are and what committee they are on. Who chairs the relevant Health Committees? Who are the Committee members? What is his/her position on the 'hot' health care issues now facing your state? If possible, review your states legislative research center online to identify names, faces and the issues. Is your local state senator/representative on the committee reviewing your interested bill? Get to know him/her! Don't let the first time you contact your legislator be when you are asking them to help with a bill or for their vote. Check the state website frequently, when it is in session to stay aware of activity and pending legislation.

5

Take Action!

Stay Informed

1. Environmental Scanning

Once you develop an understanding of the government process, then begin environmental scanning. Start by bringing information to you! Sign up for newsletters and follow on social media:

1. Your elected officials
2. Professional Organizations
 - a. American Nurses Association (ANA) [Sign up](#) for the latest updates and to get involved with advocacy campaigns.
 - b. State Nurses Association
 - c. National Kidney Foundation (NKF) [Sign up](#) for advocacy alerts
 - d. Patient Organizations
 - American Association of Kidney Patients (AAKP) [Sign up](#) for news articles
 - [Dialysis Patient Citizens](#)
 - e. State Board of Nursing
 - f. Free newsletters ([Nephrology News and Issues](#), Medical Advisor)

How do we
Advocate?

2. Join Advocacy News & Alerts via ANNA Connected

Consider joining other communities to enhance your personal experience in ANNA. Advocacy News & Alerts is a community designed for discussions related to health policy and it is utilized by the Health Policy Committee to update members on current events and activities. Use this link to join the "Advocacy News & Alerts" community in ANNA Connected: annanurse.org/advocacyalerts. Take the time to indicate the frequency of communication to ensure it is timely. To do this, go to your profile, in ANNA Connected, and click on the 'My Account' tab. Select 'Community Notifications' from the drop-down menu. From here, adjust your subscription option: Real Time, Daily Digest, No Email.

3. Contact your State Board of Nursing

Many have newsletters that you can sign up for to stay current. Request a copy of the Nurse Practice Act or find it online, by going to the National Council of State Boards of Nursing, Inc. Website: ncsbn.org. Specifically review the rules related to your organization e.g. personnel, staffing, delegation, etc. Send a letter of introduction to let them know you are available, as an expert in the field of nephrology, and available to assist them. Refer to sample letter that can be copied and pasted into an email.

Sample Introduction Letter to State Board of Nursing

(identify state) State Board of Nursing

(To find your State Board of Nursing go to the National Council of State Boards of Nursing at www.ncsbn.org)

Dear Sir/Madam:

It is my pleasure to introduce myself, *(Name)*. I am a Registered Nurse who is employed at *(name of employer)* caring for patients with kidney disease in a *(type)* facility.

I am an expert in the field of nephrology and wish to offer my assistance to the members of the Board of Nursing. Please contact me if any questions arise that involve the care of patients with chronic kidney disease (CKD); especially those who are undergoing hemodialysis, peritoneal dialysis, home dialysis, or kidney transplantation.

For your reference, I have included a State fact sheet that provides data about the CKD population in *(state)*. I can be contacted at the numbers below.

Thank you for your consideration, I look forward to working with the *(state)* Board of Nursing.

Sincerely,

Signature with credentials

Name

Address

Contact numbers

Email

4. State Nurse Practice Act (NPA)

The most important legal document for nursing is your state NPA. This law defines what the functions of nursing shall be and sets standards for education and licensure. It also addresses, in most cases very specifically, what nurses can delegate, to whom, and under what circumstances. In most states, the authority for unlicensed dialysis technicians to function lies in the delegation authority of registered nurses. But find out where this actually lies in your state. Each state has a Board of Nursing that is authorized to formulate and enforce the rules and regulations governing the nursing profession. Nurses share a responsibility to be knowledgeable about their NPA and to influence change as needed to retain current language and practices. The National Council of State Boards of Nursing at www.ncsbn.org provides links to each of the state's boards of nursing. A copy of your NPA can be obtained from your State Board of Nursing or viewed online at the individual state's Board of Nursing website. Read it! Learn how you can advise the Board if changes are needed for nephrology nursing. Consider getting a position on your state board.

The scope of registered nursing practice is similar from state to state, but a nurse's delegation authority can vary quite a bit. Action has been taken against a nephrology nurse in one state who delegated nursing tasks to an unlicensed technician. The nurse stated that non-nurses in her state routinely performed these tasks and that no injury resulted from the delegation of these tasks. In

reviewing her state NPA, it was evident that these tasks should not have been delegated. The nurse was facing the possibility of disciplinary action including fines, probation, and/or loss license to practice. Common practice does not ensure that the practice is legal in your state. Because many practice questions are unanswered, nurses should be concerned with reducing their risk of practicing outside their NPA by asking themselves the following questions:

- Does my NPA address the delegation authority of the RN? Has the board taken a position specific to delegation to unlicensed personnel in dialysis?
- If so, what tasks can and cannot be delegated, and under what circumstances?
- Is the task I am about to perform something that the prudent nurse would render under the same or similar circumstances? Is this action explicitly addressed in my respective NPA or its rules and regulations?
- To what standards will I be held in performing nursing care?

5. Contact your State Nurses' Association

Introduce yourself to the Health Policy staff or individual(s) designated for that role and let them know that ANNA monitors legislation pertinent to ESKD/nursing issues. Ask for their assistance in orienting you to your state legislature. Ask for their website address and ask that you be put on their Health Policy Committee's listserv and/or alert list. We encourage you to become a member of your state association. Ask how you can be of assistance to them.

6. Contact the State Department responsible for health oversight (e.g. Department of Public Health, Department of Health Services, Department of Community Health)

Inquire as to the existence of an ESKD or Chronic Kidney Disease Advisory Committee, and ask for contacts in the department who are responsible for ESKD, recognizing that ESKD issues may be handled by several interdepartmental personnel, including those involved with Certificate of Need, Federal/State Survey & Certification, etc. The goal is to establish contact within the department for future reference. Again, ask how you can be of assistance to them.

7. Utilize a State Fact Sheet

One way to educate others and elected officials, or to make ESKD issues relevant to them, is to show them information about kidney disease and treatment of kidney failure in their jurisdictions (districts or states). The state fact sheet is a great tool and contains concise that most legislators do not have available. ANNA's Website provides a link to state fact sheets, obtained from the Kidney Care Partners at kidneycarepartners.com/kidney-disease/#map. Simply click on your state and you will see some general statistics about CKD as well as the specific facts for your state for the number of individuals with ESKD and the number of dialysis centers.

Additional statistical date can be obtained from the Network's Annual Report. This information can be obtained from the ESRD Network Forum's website: esrdnetworks.org. Network offices will generally send a copy of the Annual Report(s) if requested. Some states have Renal Disease Programs that you can obtain information on the services offered by that program.

8. CongressWeb

ANNA maintains Take Action! on its website so that members can communicate quickly and easily with elected representatives about issues that affect nephrology nursing practice.

ANNA works closely with Congress, government agencies, and nephrology care advocacy organizations to help ensure patient access to quality nephrology care. Use Take Action (Congress Web) for these tasks:

- Find ANNA Legislation Priorities / Fact Sheets
- Find your representatives
- Current action items: Current letters drafted to address issues important to nephrology nursing and ready to be sent by you!

CongressWeb allows you to contact your elected representatives about issues important to nephrology nurses by clicking on a button. Be sure to check the site regularly for new action items!

9. Communication with elected officials

a. Build a Relationship with your Elected Officials

It is important for nurses to build strong relationships and allies in state and federal government. To do this you will need to get to know your legislators and where they stand on issues important to nephrology nurses and our patient population. Many do not understand the issues impacting kidney disease and the care we provide. Offering your services and expertise to them will allow them to make knowledgeable decisions. Educating your representatives will become a benefit when you are asking them to pass a bill that is meaningful to nursing, nephrology nursing, or to our ESKD patients. Be sure to maintain the relationships with your legislators.

- Attend their forums or town hall meetings.
- Speak about ESKD issues and legislation you would like to see them support.
- Hold them accountable to promises that they have made regarding certain legislation.

Begin with an introduction letter. Remember you are an expert and can offer your expertise as they look at health policy issues. Refer to sample letter - copy and paste into email.

Sample Introduction Letter to Elected Officials

Date:

The Honorable **[First Name Last Name of Member of Congress]**
United States **[House of Representatives or Senate]**
Washington, DC **[20515 or 20510]**

Dear **[Representative or Senator] [Last name of Member]**

As a constituent and nephrology nurse, I am writing to introduce myself. I am a Registered Nurse employed at **[name of employer]** caring for patients with kidney disease in a **[type]** facility.

I am an expert in the field of nephrology and wish to offer my assistance to you and your staff in any areas that involve the care of patients with chronic kidney disease (CKD); especially those who are undergoing hemodialysis, peritoneal dialysis, home dialysis, or kidney transplantation.

For your reference, I have included a state fact sheet that provides data about the CKD population in **[state]**. I encourage you to contact me about any of the information on this sheet that you might have questions about.

I look forward to working with you and members of your staff.

Sincerely,

Name, Degree
Home Address (Street, city, state, zip)
Phone number and email address

b. Continue Ongoing Relationships with Representatives

Keep Representatives informed of the progress of health policy initiatives as there are many opportunities to intervene and support them. Regular contact with representatives. Representatives are more likely to respond to your request with regular contact. Ensure regular communication with your representatives:

- Write letters on issues important to nephrology nursing, including use of CongressWeb.
- Follow up on any of your asks – it allows you to know where your representative stands on issues.
- Use opportunities to keep them up to date on progress, or lack of progress, of health policy initiatives.
- Invite them to your area of practice including dialysis facilities, CKD clinics, transplant center or acute care area.
- Work with your ANNA chapter and make appointments to meet your representatives as a group. There is more power in groups.

10. VIP Site Visits (on site/virtual)

VIP Site Visits are defined as: *any activity that is dedicated to educating policymakers and their staff about the needs of patients suffering from or at risk for end stage kidney disease (ESKD).*

ANNA encourages nephrology nurses to educate policymakers, their staff members, or other VIP's about the needs of patients suffering from or at risk for ESKD. The objective of these visits is to educate policymakers about kidney disease, treatment options, and the legislative issues facing the kidney community. Meeting with government officials or their staff is an effective way to share a message about a specific policy, legislation, or funding issue. Show them - firsthand - how policies affect patients! ANNA members are encouraged to invite Congressional delegates, state legislators, local officials, and State Board of Nursing staffers to visit local dialysis facilities, CKD clinics, transplant centers and acute care areas. Refer to Chapter 6 for details of scheduling a visit.

11. Visit Legislators

If a virtual/on site visit is not possible, plan to visit the legislator. Schedule a virtual or in-person meeting at the local office to meet with either the legislator or staffer. Include other ANNA members, as appropriate. The objective is to educate policymakers about kidney disease, treatment options and the legislative issues facing the ESKD community.

12. Go to the Hill!

a. ANNA Health Policy Workshop

ANNA hosts a Health Policy Workshop every two years for ANNA members, held in odd numbered years (e.g. 2019, 2021, etc.) The workshop includes appointments with elected officials from the attendee's home districts, as well as speakers from various government and healthcare agencies.

b. Nurse in Washington Internship (NIWI)

Sponsored by the Nursing Organizations Alliance, the NIWI program provides nurses the opportunity to learn how to influence health care through the legislative and regulatory processes. Participants learn from health policy experts and government officials, network with other nurses, and visit members of Congress. For more information about the NIWI program, visit The Alliance website at nursing-alliance.org.

13. Practice and Prepare for Succinct Conversations

Communicate with your representatives through email, USPS, or phone calls to their office. Keep your messages simple, concise, and brief when discussing an issue. Tips for communicating your support or non-support with your representatives about current legislation and policy issues:

- Identify constituency – being a constituent gives you priority and when they know you are keeping track of what they are doing, they are more likely to support your asks
- Share personal stories –personal/family stories are remembered and can be a powerful tool
- Keep stories brief and to the point – 2 minutes or less or they may lose interest
- Provide facts, data, and figures that help support your case
 - Use State Fact Sheet to educate on issue of importance
- Clearly communicate what you are asking for, e.g. cosponsor/support/not support a bill
- Offer your expertise as a nephrology nurse

14. Nephrology Nurses Week

Nephrology Nurses Week was developed to honor the dedicated nephrology nurses who care for patients with kidney disease, ANNA has designated the second full week in September each year as Nephrology Nurses Week. As an advocate, proclamations to recognize this honor can be requested. Refer to Tips for Getting an Official Proclamation from Your Community or State and Sample Template in Chapter 7 of this Handbook.

13. National Kidney Month / World Kidney Day

- National Kidney Month:** March is National Kidney Month, a time when communities across the country raise awareness about kidney disease.
- World Kidney Day:** World Kidney Day is a global campaign aimed at raising awareness of the importance of your kidneys.

Advocacy also involves educating and raising awareness about kidney disease. There are many opportunities to raise awareness. Refer to the International Society of Nephrology, World Kidney Day (WKD) website for more ideas: worldkidneyday.org. The Website also

contains a wealth of campaign material including the WKD logo, posters, and CKD infographics. There are many ideas that can be considered:

- Educate staff
- Educate patients
- Celebrations
- Recognize an important person
- Social media promotional campaign
- Use the available posters
- Light up a building
- Ring the bell of your town hall or church

Other suggestions include:

- Utilize Healthy People 2020 Chronic Kidney Disease objectives and interventions [healthypeople.gov/2020/topics-objectives/topic/chronic-kidney-disease](https://www.healthypeople.gov/2020/topics-objectives/topic/chronic-kidney-disease)
- Incorporate the CDC Chronic Kidney Disease Initiative [cdc.gov/kidneydisease/index.html](https://www.cdc.gov/kidneydisease/index.html)
- Use the National Kidney Foundation 6-Step guide to protecting Kidney Health [kidney.org/atoz/content/sixstepshealthprimer](https://www.kidney.org/atoz/content/sixstepshealthprimer)

6

Site Visit Planning Guide

Step-by-step instructions are provided to guide and help you with the activities associated with scheduling a visit with your policy makers, the “how-to” for conducting the visit, and the follow-up after the visit to help you to build a long-term relationship.

Step 1: The Invitation

Invite elected officials to visit your nephrology program. Begin by identifying who you will invite, consider:

- **Federal Lawmakers** (i.e., Senators and Representatives) Implement laws and policies for programs such as Medicare which reimburse for dialysis treatments, medications, and services.
- **State Lawmakers** (Senators, Representatives, and Governors) Impact funding for state programs, including Medicaid funding for dialysis treatments, medications, and services.
- **Local officials** (Mayors, Council Members, and Aldermen) May influence transportation or other local policies.
- **Candidates running for office** May value the opportunity to visit and be photographed in a healthcare setting.

Contacting your Members of Congress is easier than ever, thanks to ANNA’s Legislative Action Center. To find it, go to the ANNA Website, select the Health Policy tab, and then the “Take Action” link. ANNA’s Legislative Action Center provides all the contact information you need for your policymakers. All you need to do is enter your zip code!

One way to get started is to call the lawmaker’s district office:

- When the receptionist answers the phone, clearly state your first and last name, your city and state, and **ask for the “Scheduler.”**
- If you are asked why you are calling, let the receptionist know that you are calling to invite **[Policymaker’s Title (e.g. Senator), last name]** to visit a nephrology program in **(city, state)**.
- The receptionist should forward you to the Scheduler directly or you may be put into voicemail. **If you are forwarded to voicemail** - leave your name, your city and state, your contact phone number, and the reason you are calling.
- When you speak to the Scheduler introduce yourself again. Tell the Scheduler why you are calling. For example: *“I am calling to invite [Policymaker’s Title, last name] to visit the [insert name of facility/program] in [city and state] to take the time to educate (Policymaker’s Title) about quality kidney care and the patient population for which ANNA members care.”*
- Generally, the Scheduler will take your information to have the lawmaker’s Healthcare Legislative Assistant or the lawmaker’s “Staffer” call you back.
- When the Legislative Assistant returns your call, introduce yourself again.
- Request to schedule a visit to your nephrology program, providing details about the visit. *For example:* When making the request for a visit by the lawmaker, extend the invitation to the Legislative Assistants as well. Legislative Assistants often are the people who read all the material on a specific topic and then provide a summary of the information to the lawmaker.

- **Speak with the confidence** that your lawmaker will jump at the opportunity. For example: *“Which day would be convenient for [Policymaker’s Title, last name] and you [Legislative Assistant, name] to visit the [insert name of facility/program]”?*
- Generally, the Assistant will indicate that he/she will need to check the lawmaker’s calendar and get back in touch with you. **Make sure the Assistant has your contact information (phone number and e-mail address).**

Ask the office’s preferred method of communication.

- Some lawmaker’s offices will ask you **to fax a letter of request** for a visit to their office. If so, ask to whose attention the fax should be sent and confirm the fax number.
- If you are faxing the request, make a follow-up phone call to ensure the letter of request was received by fax.
- For example: *“Hello, this is [your name] from [state]. I wanted to call to confirm that you received the scheduling request to visit our nephrology program. I faxed this invitation to you on [date invitation was sent to the office].”*
- The lawmaker’s office may ask you to **send the request by e-mail**. Ask for the name and e-mail address of the staffer to whom the e-mail should be sent.
- Some lawmaker’s offices prefer **contact by phone**. If this is the case, you may ask whom you should call to follow up on your request and if that person has a direct line.

A sample invitation letter is provided here. You may copy and paste into an e-mail or fax document.

Sample Invitation Letter

Date

The Honorable **[First Name Last Name of Member of Congress]**
 United States **[House of Representatives or Senate]**
 Washington, DC **[20515 or 20510]**

Dear **[Representative or Senator] [Last Name of Member]**:

As a constituent and a nephrology nurse, I am writing to cordially invite you and members of your staff to tour the **[insert name of facility/program]** in **[city and state]**. I am an expert in the field of nephrology and wish to offer my assistance to you and your staff in any areas that involve the care of patients with chronic kidney disease (CKD); especially those who are undergoing hemodialysis, peritoneal dialysis, home dialysis, or kidney transplantation.

Visiting **[insert name of facility]** will give you and your staff an opportunity to learn about kidney disease as well as the daily operations of a Nephrology program. This tour provides an excellent opportunity to learn first-hand about quality kidney disease care from your constituents. Past Congressional participants remarked that they felt better informed on the issues surrounding quality kidney disease care.

I hope that you and your staff are able to tour the **[insert name of facility/program]** in **[city and state]** on any date that is convenient for the Senator/Representative’s schedule. I would be pleased to help coordinate a tour for you and your staff and will follow up with your office to schedule the tour.

Thank you in advance for your consideration of this request.

Sincerely,

Name, Credentials

Home address (Street, City, State, Zip)

Phone Number, E-mail address

Step 2: Finalize the Visit

Continue communication with the lawmaker's Legislative Assistant **until you have a commitment.**

Be persistent. If the Scheduler or Assistant does not return your call(s) within a day or two at the most, call or e-mail again. It is acceptable to be a polite squeaky wheel.

Clarify:

- Date and time of scheduled visit.
- Names of those attending from the lawmaker's office.

Use this information to plan:

- Areas to be toured.
- Light refreshments for ending the visit in a conference room or break room.

Prepare:

- Prepare the clinic staff and patients for the visit event.

Prior to the visit:

- Learn more about what issues are important to ANNA and if the policymaker sits on any relevant committees. For additional resources, be sure to visit the ANNA Website at annanurse.org/advocacy.
- **A week or two before the visit, confirm the appointment** with your contact. The Congressional schedule changes frequently and is sometimes beyond the lawmaker's control. The lawmaker's office may not remember to notify you in a timely manner, so, checking in is a good idea.
- **The day before the visit, it is a good idea to confirm the appointment** with your contact. The day may remain the same, but the timeframe may change on short notice.

Step 3: Conducting the Visit

Meeting with Members of Congress and/or their staff, local lawmakers, and local government officials is a terrific way for nephrology nurses to communicate with policymakers on issues of interest and priority.

Inviting lawmakers and their staff to visit your nephrology program enables you to educate them about your concerns, offer yourself as a resource, and establish a relationship that can result in support for the American Nephrology Nurses' Association (ANNA) health policy priorities.

Prepare and be on time. Have two to three "greeters" at the door to greet the visitors.

- **Select a primary spokesperson** and determine who in the group will be raising which points and requests.
- **Open by thanking the lawmaker and/or staffer for his/her time.** Be sure that everyone in your greeting group identifies him or herself—first and last name and connection to nephrology nursing and kidney disease.

- Remember to mention that you are a constituent.
- If the Member of Congress or staffer has been helpful in the past or has taken action that you appreciate, be sure to say thank you and **acknowledge his/her support.**
- **Prepare the visitors for what they will see.** (We find it hard to believe, but sometimes the sight of blood, even if neatly contained, bothers some people!)
- **Brief the visitors about HIPPA and Infection Control requirements** in a conference room or break room before beginning the tour.
- **Be brief and concise.** Typically, a visit will last an hour or less.
- **Plan to cover only a few (one to three) issues.**
Prepare your talking points beforehand to ensure that you and your colleagues stay on message.
- **Teaching opportunities might include:**
 - The prevalence of kidney disease in the population; the types of diagnoses.
 - One resource for this type of information is the State Fact Sheets.
 - The goals of a Chronic Kidney Disease (CKD) program.

Unit Tour:

Introduce the lawmaker and staff to select patients who have agreed in advance to meet with the visitors. Review your area of kidney care:

- Talking with patients during the tour has been evaluated as educational
- Review how dialysis works
- Discuss types of therapy offered - nocturnal, self-care
- Describe requirements for water treatment by touring the water treatment area with the Biomedical or Technical Manager
- Home Training - Peritoneal Dialysis, Home Hemodialysis
- Discuss types of therapy offered – CAPD, CCPD, and/or HHD
- Discuss processes for transplant and post-transplantation care

If asked a question to which you do not know the answer, acknowledge that you will need to follow up later with the answer, and remember to do so. **Do not assume that the lawmaker or staffer is very knowledgeable about any of the issues you are discussing.** Do not be afraid to take extra time to find the right answer and “get back to” the person asking the question. Providing your answer is just another chance to be in touch and remind your policymaker and/or his/her staff of your requests.

Return to the conference room or break room to discuss healthcare policy issues.

In your visit preparation, plan to spend these last few minutes with your visitors in a comfortable environment. Availability of light refreshments may assist in creating this environment.

- Provide a personal story or real-life illustration of how patients (constituents) are impacted by kidney disease. Personal stories are remembered more easily than statistics.
- Discuss how policy change (e.g., increased funding for the Nurse Reinvestment Act, Medicare/Medicaid reimbursement changes for End Stage Renal Disease prevention and treatment) will have an impact on your community.
- For resources for this type of information look on the ANNA Website, annanurse.org/advocacy.

- Use evidence and statistics to support your position, particularly any local, regional, or state data.
- Be concise and honest about the issue(s) and the solution(s).
- Provide a resource packet to give the visitors.
- Early in the tour indicate that you have State Fact Sheets that you will provide them at the end of the visit.
- Clarify if follow-up is needed for additional information.
- Summarize your requests of the Member or office and any responses the Member or staffer has given you over the course of the visit to ensure that you are clear on where he or she stands on the issues.
- Express thanks and appreciation for his or her time, interest, and courtesy.

Step 4: Follow Up

Send a thank-you note to the lawmaker or staffer referencing the date of the visit and the issues you discussed. Again, e-mail is preferred.

- Include answers or information that the Member or staffer requested.
- Develop a plan to keep in touch with the Member or staffer on a periodic basis to maintain and strengthen the relationship and be available as a local resource on nursing and kidney disease issues.
- A sample thank you letter is provided here which you may copy and paste into an e-mail or fax document.

Sample Thank You Letter

Date

The Honorable **[First Name Last Name of Member of Congress]**
 United States **[House of Representatives or Senate]**
 Washington, DC **[20515 or 20510]**

Dear **[Representative or Senator] [Last Name of Member]:**

As a constituent and a nephrology nurse, I am writing to thank you and **[list the members of his/her staff in attendance]** for taking time out of your busy schedules to visit the **[insert name of facility/program]** in **[city and state]**.

As we discussed on August **[date]**, **[include a couple of sentences reiterating the issues you discussed with the Congressional Member on the tour]**.

I hope that you and your staff found the tour of **[insert name of facility]** an excellent opportunity to learn more about kidney disease from your constituents. I look forward to hearing from you about the actions you have taken on the issues we discussed. Should you or your staff have any questions or need more information on kidney disease or nursing issues, please feel free to contact me.

Sincerely,

Name, Degrees
 Home address (Street, City, State, Zip)
 Phone Number, E-mail address

Quick Steps Checklist

Activity	Who	Completed	Notes
Step 1 - Invite			
Who (Invited Officials' Names)			
When (Date of Visit)			
Where (Location of Visit)			
Step 2 - Finalize			
Confirm: Date, Time, Place of Visit			
Confirm: Facility Staff Members in Attendance			
Print: - State Fact Sheets - District Information Learn ANNA Issues			For State Fact Sheets, click here . To learn about ANNA's legislative priorities, click here .
Reconfirm Visit Week Prior			
Arrange for light refreshments			Optional
Prepare forms: HIPPA, consents)			
Step 3 – Conduct Visit			
Visit Complete			
Step 4 – Follow Up			
Send “thank you” e-mail to visitors.			
Follow up on other issues.			

7 Proclamations

Tips for Getting an Official Proclamation from Your Community or State

Getting a proclamation is one of the most significant things your facility or chapter can do to draw local and national attention for Nephrology Nurses Week, and it can be easy if you know how to do it. In many areas, a mayor or governor can issue a proclamation without action from the city council or state legislature.

Getting a Proclamation issued without legislative action:

1. *Call your local mayor or governor's office* to determine how proclamations are issued. Contact information can be found on your town's Website. Be prepared to learn that it may take a few months.
2. *Identify a city council member or mayor to sponsor the proclamation.* Your local mayor or governor's office can direct you to a city council member who may sponsor your proclamation. If you already know a city council member, it should be easy to garner assistance. Have your materials ready when you call to ask for support, such as the sample proclamation below.
3. *Determine the approval process.* Work with your sponsor to determine a schedule for approving your proclamation. Offer letters of support or speakers if needed (see step 4).
4. *Elicit support for your proclamation from other leaders in your city or state. Ask your co-workers or fellow ANNA members to contact their mayors, city council members, or local and state officials by writing letters or scheduling visits encouraging support of the proclamation.*
5. *Ensure your sponsor sees your proclamation through to the final stages. Follow up with your sponsor throughout the process to make sure things are on track.*
6. *Express your thanks after the proclamation is issued.* Ask your sponsor to participate in any special events your facility or chapter has planned for Nephrology Nurses Week. Remember to inform the media about Nephrology Nurses Week and the recognition you have received. After the week is over, send thank you letters to your sponsor and any city council members or staff who helped you through the process.

Getting a Proclamation issued when legislative action is required:

1. *Start the process immediately* if you need to work through the city council or state legislature to obtain a resolution. You will know if you need legislative action after you call your local mayor or governor's office.
2. *Identify a sponsor for the resolution.* The sponsor must be a state representative or state senator. Find someone who is supportive of nursing or who has voiced an interest in health care issues. This could also be an opportunity to educate a government official not familiar with nephrology nursing or health care issues. Of course, it is always easier to work with someone with whom you have a relationship.

Tips for Getting an Official Proclamation from Your Community or State

1. *Determine how the legislation will move forward.* Keep in touch with your sponsor to ensure passage of the resolution. You may also be asked to send someone to speak on behalf of the resolution at a hearing. Have materials prepared and be ready to share insight about the contributions nephrology nurses make to their patients and the community.
2. *Elicit support for your resolution from other leaders in your city or state.* Ask your co-workers or fellow ANNA members to contact their mayors, city council members, or local and state officials by writing letters or scheduling visits. The legislature will appreciate hearing from constituents and knowing they have their constituents support on particular issues.
3. *Follow up with your sponsor.* Legislators are busy with many issues each day.
4. *Stay in touch with your sponsor* and identify other steps you can take to ensure passage.
5. *Express your thanks after the resolution is passed.* Ask your sponsor to participate in any special events your facility or chapter has planned for Nephrology Nurses Week. Remember to inform the media about Nephrology Nurses Week and the recognition you have received. After the week is over, send thank you letters to your sponsor and any city council members or staff who helped you throughout the process.

Sample Proclamation

WHEREAS, nearly 30 million Americans suffer from kidney disease and every year many *[insert your city, state]* citizens, including children, adults, and elderly individuals, are diagnosed with kidney disease; and

WHEREAS, the depth and breadth of the nephrology nursing profession meets the different and emerging kidney disease and other health care needs of the population of *[insert your city, state]*; and

WHEREAS, the American Nephrology Nurses Association is working to advance quality care to Americans with kidney disease before they suffer complete organ failure, increase awareness in local communities, positively influence patient outcomes, and keep nephrology nurses abreast of the latest treatments and kidney-related research; and

WHEREAS, nephrology nurses function as educators, direct caregivers, and coordinators to help patients manage their lives while effectively dealing with their health issues; and

WHEREAS, the number of new patients diagnosed with kidney disease has doubled in each of the last two decades, the demand for nephrology nurses will persist to expand as this trend is expected to continue; and

WHEREAS, more qualified nephrology nurses will be needed in the future to meet the increasingly complex needs of patients who are experiencing, or are at risk for, kidney disease; and

WHEREAS, along with the American Nephrology Nurses Association, the *[insert the name of your facility or local ANNA chapter]* has declared the week of September 8 through 14, 2019, as Nephrology Nurses Week to celebrate and honor the unselfish work nephrology nurses perform each day to maintain the health of thousands of individuals with kidney disease, therefore be it

RESOLVED, that I, *[insert your Governor's/Mayor's name and title]* designate the week of September 8 through 14, 2019, as Nephrology Nurses Week and ask that all residents of *[insert your city, state]* join me in honoring the nephrology nurses who care for patients with kidney disease, and be it further

RESOLVED, that the residents of *[insert your city, state]* celebrate nephrology nursing's efforts to advance patient care and reduce the incidence of kidney disease and show our appreciation for *[insert your city]* nephrology nurses not just during this week, but at every opportunity throughout the year.