



## **SPEAKING OUT ON BEHALF OF PEDIATRIC NEPHROLOGY ASPEN'S ADVOCACY GUIDE TO HOW AND WHY YOU CAN MAKE A DIFFERENCE**

The American Society of Pediatric Nephrology (ASPEN) recognizes that decisions made in the halls of Congress influence how pediatric nephrologists conduct research and care for their patients. It is through the strength of many voices and one message that ASPEN can influence, and where appropriate, change laws, regulations, and public programs to accomplish our mission: to promote optimal care for children with renal disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology.

Public policy advocacy is an important tool in educating decision-makers in Washington and back home about the critical issues affecting the pediatric nephrology community and our patients. If we do not take part in this important process, the needs of the pediatric nephrology community and our patients will be forgotten, or worse, decisions will be made that negatively affect our ability to conduct research and care for our patients. Successful advocacy depends on the involvement of many. Therefore, it is critical that every ASPEN member get involved in educating Congress, state legislators, and even the White House and federal agencies about what's important to you.

This handbook is designed to enable you to take part in state and federal advocacy efforts. The following pages contain helpful tips on how to call, visit, or write your members of Congress and your state legislators.

Most of the contents in this guide are simple, common sense suggestions. Advocacy is not complicated or technical, but does require dedication, time, and perseverance. The success of ASPEN's advocacy efforts depends on you, and we hope you will use this information to speak out on behalf of your patients and profession.

## GETTING YOUR MESSAGE ACROSS IN CONGRESS

### WHY GET INVOLVED?

- ❖ To promote the health of your patients.
- ❖ It's your **right** to let elected officials know how you feel about important issues.
- ❖ To protect the interests of your profession and how you practice.
- ❖ It's your **responsibility** to speak out on matters that affect you.

### HOW DO YOU GET INVOLVED?

- ❖ **Learn** all the facts you need to make the strongest argument for your position. Utilize ASPN's issue briefs, available at <http://www.aspneph.com/PublicPolicy.asp>, to better understand some of the important policy issues affecting our specialty and our patients.
- ❖ **Organize** your arguments and encourage others to get involved. If you are eager to work more closely on the development and dissemination of ASPN's public policy agenda, please plan to attend Public Policy Committee (PPC) meetings. To learn more about the Committee, or to become a member, please email [info@aspneph.com](mailto:info@aspneph.com).
- ❖ **Contact** your elected officials. Invite a lawmaker or their staff to visit your dialysis unit and educate them face-to-face about what it is you do. Help them understand that the decisions they make have real implications on how you treat your patients.
- ❖ **Express** your views in a clear and concise manner, and respectfully ask for a commitment from your elected officials. One way of expressing your views is to respond to ASPN's legislative alerts. These timely alerts are sent to the membership when critical bills, amendments, or votes are about to take place that specifically impact your research and practice. Use these alerts to express your position on the topic, and why the particular policy issue is important to you, their constituent.

## WHAT ARE THE METHODS?

- ❖ **Personal visits** are the most effective means of getting your point across. If you are unable to meet with your elected officials in Washington, DC, schedule a meeting in one of their district offices in your state.
- ❖ **Written communication** also gives you an opportunity to let your elected officials know where you stand.
- ❖ **E-mail and phone messages** allow you to convey your message when time is of the essence.

## WHEN DO YOU GET INVOLVED?

- ❖ ASPN's legislative consultants monitor activities of Congress and the federal agencies. They share their information and analysis of these activities with the Society, and work with the PPC to ensure ASPN members take action in a timely manner to promote the best policy outcomes for our patients and profession.
- ❖ Generally speaking, it's best to express your views when legislation is in the early stages of review by a congressional committee. It's also important to remember that issues can arise on short notice. In those instances, quick action on everyone's part can mean the difference between success and failure.

## WHAT TOOLS TO DO YOU NEED TO GET INVOLVED?

- ❖ A desire to get involved. Decisions made by Congress directly impact your ability to conduct research and care for your patients. Your involvement is critical in preventing these decisions from harming your research or your practice.
- ❖ A commitment to act in a timely manner. Advocacy fails when it's sporadic and untimely. Therefore, take a few minutes to respond to ASPN's legislative alerts within a day or two after receiving them.
- ❖ A willingness to establish and sustain relationships with Members of Congress. Meeting with a lawmaker and/or staff is only the beginning in building a successful relationship. Once you educate a lawmaker about pediatric nephrology and the critical issues facing the profession, it is critical to nurture that relationship. For example, if your legislator voted for legislation providing health insurance to chronically-ill children, send a thank-you note. It is the reminder that you are monitoring his or her actions, keeping the legislator accountable for their actions.

## **HELPFUL HINTS WHEN VISITING A CONGRESSIONAL OFFICE**

### **MAKE AN APPOINTMENT**

- ❖ It is important to make an appointment as early as possible. If you don't have the telephone number for the congressional office you want to visit, call the U.S. Capitol switchboard at (202) 224-3121.
- ❖ If your Senator or Representative is unavailable, ask to meet with the legislative assistant who handles the issue of interest to you.

### **BE PREPARED**

- ❖ If you don't know your Member of Congress personally, try to learn a bit about his/her background and previous occupation. Additional biographical information about your senators and representatives can be found at <http://www.congress.org/congressorg/home/>. Find out, if possible, where the Member stands on issues you will be discussing.
- ❖ Review what you want to say in advance of your meeting, and familiarize yourself with ASPN's legislative issue briefs.
- ❖ Explain how the issues you raise affect you and your community. Keep your message personal. Do not provide national statistics that the legislator could find online. Rather, keep your message short, simple and personal. Remember, all politics are local.

### **BE BRIEF**

- ❖ Since legislators and their staff have extremely busy schedules, plan on getting your message across in 5 to 10 minutes. Don't get sidetracked into small talk-make your time really count.

### **LISTEN CAREFULLY**

- ❖ Be prepared to answer questions. If you don't know the answer to a question, admit it and offer to provide the answers later. Contact ASPN for any additional information you need, and include this information in your follow-up/thank you letter to the office.

## **BE FIRM**

- ❖ Try to find out exactly where your legislator stands on the issues, particularly as they affect your organization and its members. Ask what action he or she intends to take, and don't be afraid to press for specifics.

## **FOLLOW UP**

- ❖ Send a thank-you letter to the legislator and/or staff aide; include a summary of your views, together with any additional information that may be relevant. You may also want to make a follow-up call a week or two after your visit.

## **WRITING AN EFFECTIVE LETTER TO MEMBERS OF CONGRESS**

### **KEEP IT BRIEF AND TO THE POINT**

- ❖ Keep your letter reasonably brief and limit your subject matter to a single issue. State the issues clearly in the first paragraph, so that the letter can be assigned to the appropriate staff aide.

### **PERSONALIZE YOUR LETTER**

- ❖ Explain your position, and give the lawmaker reasons for supporting it. Make your communication your own. Stress how you—the lawmaker's constituent—will be affected and cite specific examples if you can. Don't limit your correspondence to slogans or phrases from a newsletter or form letter. Your own words will make the crucial difference.

### **BE POSITIVE**

- ❖ Frame your concerns in a way that captures the lawmaker's attention. Show your awareness of the lawmaker's past actions (i.e., cite the lawmaker's past voting record, public announcements, what they said at a recent town hall meeting etc.)

### **ASK FOR A RESPONSE**

- ❖ To obtain a personal response, ask a thoughtful question about an issue that concerns you. Example, at the end of your letter - "Can I count on your support?"

## FOCUS ON THE MERITS

- ❖ Never threaten or beg a Member of Congress. Always appeal to the lawmaker on the merits of an issue.

## CONTACT YOUR LEGISLATOR ONLINE:

- ❖ United States Senate

[www.senate.gov](http://www.senate.gov)

- ❖ United States House of Representatives

[www.house.gov](http://www.house.gov)

[www.house.gov/writerep](http://www.house.gov/writerep)

- ❖ Members of Congress must be addressed properly in any correspondence. Below are the standard salutations for writing your lawmakers.

If you are corresponding with a senator:

The Honorable \_\_\_\_\_  
United States Senate  
Washington, DC 20510

If you are corresponding with a representative:

The Honorable \_\_\_\_\_  
U.S. House of Representatives  
Washington, DC 20515

## SAMPLE LETTERS TO CONGRESS

### REQUESTING SUPPORT ON AN ISSUE

The Honorable (*Representative's/Senator's first and last name*)  
(Office location)  
U.S. House of Representatives or U.S. Senate  
Washington, DC 20515 (House) 20510 (Senate)

Dear Representative/Senator (last name):

As a practicing pediatric nephrologist who treats children with kidney failure, I am writing to ask for your cosponsorship of H.R.3282/S.2320, the "Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2007", a bipartisan bill introduced by Representatives Dave Camp (R-MI) and Ron Kind (D-WA) in the U.S. House, and Senators Richard Durbin (D-IL) and Thad Cochran (R-MS).

Medicare covers the cost of kidney transplantation for eligible end-stage renal disease (ESRD) beneficiaries, including those vulnerable children in desperate need of the gift of life. Successful transplantation frees these patients from the rigors of dialysis, which must be performed three to four times per week, if not daily, and markedly improves their quality of life. Although Medicare pays for the kidney transplant, coverage for the immunosuppressive drugs required for survival of the transplanted kidney ceases for most pediatric ESRD beneficiaries after 36 months. Without these drugs my pediatric patients will suffer loss of the transplant and require dialysis, increasing Medicare costs substantially.

Currently, the only Medicare beneficiaries eligible for lifetime coverage of transplant drugs are those who were and are eligible for Medicare because they are aged or disabled and whose transplant was paid for by Medicare. Other ESRD patients have a limited benefit or no benefit at all – including several of my current patients. The *Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2007* addresses these gaps. Specifically, the bill would extend coverage for immunosuppressive drugs furnished to beneficiaries under the Medicare program who have received a kidney transplant and whose entitlement to coverage would otherwise expire.

Reforming our health care system to allow for quality access to post-transplant treatment for pediatric kidney disease patients will not only decrease the unnecessary utilization of Medicare dialysis services, but more importantly, improve the quality of life for this delicate population.

I respectfully ask for your support of H.R. 3282/S.2320, and thank you for your continued leadership for our district (*insert "state" if written to a senator*).

Thank you for your help!

Sincerely, (Your name) (Your contact information)

## **THANK YOU FOR MEETING/SPEAKING WITH**

The Honorable (*Representative's/Senator's first and last name*)

(Office location)

U.S. House of Representatives or U.S. Senate

Washington, DC 20515 (House) 20510 (Senate)

Dear Representative/Senator (*last name*):

I am writing to thank you (*your staff, insert name of appropriate staff member*) for taking the time to meet with (*or speak with*) me on (*insert date and time if appropriate*) about the importance of reforming our health care system to allow for quality access to post-transplant treatments for pediatric kidney disease patients.

I was pleased to hear your interest in improving access to post-transplant treatments for the kidney disease population that would result in better quality of life and fewer hospitalizations for this delicate population. As I indicated during our discussion, I am happy to be a resource to you if you or your staff (*insert name*) has any questions about pediatric kidney disease and transplantation.

Thank you for your continued leadership for our district (*insert "state" if written to senate office*).

Sincerely, (Your name) (Your contact information)

## **THANK YOU FOR COSPONSORING**

The Honorable (*Representative's/Senator's first and last name*)

(Office location)

U.S. House of Representatives or U.S. Senate

Washington, DC 20515 (House) 20510 (Senate)

Dear Representative/Senator (*last name*):

I am writing to thank you for cosponsoring H.R. 3282, the "Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2007," a bipartisan bill introduced by Representatives Dave Camp (R-MI) and Ron Kind (D-WA). Improving access to post-transplant treatments for the pediatric kidney disease population will result in better quality of life and fewer hospitalizations for this delicate population. This bill will ensure high quality kidney care and improve post-transplant health care for the Medicare end-stage renal disease program.

Again, my sincere thanks for your support of H.R. 3282!

Sincerely, (Your name) (Your contact information)