

# AAKP & YOU

*American Association of Kidney Patients*  
*The Voice of All Kidney Patients™*



*How To Be Your Own Public Policy Advocate*



November 4, 1971, was an important day for America's kidney patients. In the most dramatic plea ever made on behalf of kidney patients, Shep Glazer, Vice-President of the National Association of Patients on Hemodialysis (NAPH), which was later renamed the American Association of Kidney Patients (AAKP), testified before the House Ways and Means Committee while attached to a fully functioning artificial kidney machine. Glazer asked the Committee to give the American people a comprehensive

health insurance program which would fully protect them in case of catastrophic illness. He said that kidney disease is unique because kidney patients, unlike other chronically ill patients, can return to a fairly normal life. He emphasized that we are productive members of society, pay our taxes and circulate money back into the country's economy.

Shortly after the Congressional hearings, Congress approved the legislation that led to the implementation of the Medicare End-Stage Renal Disease (ESRD) Program. It provided federal funding for those patients who required dialysis due to kidney failure. Prior to the Medicare ESRD Program, treatment was limited to a few individuals, as the costs were high and only a limited number of dialysis machines existed. Those who lived near hospitals with dialysis machines often appeared before specially appointed committees to argue for

treatment. Those approved by the committee received dialysis, while those denied were left to die of kidney failure.

The efforts of Glazer and AAKP demonstrate the lasting power of advocacy. Today, AAKP continues the mission of Glazer and the numerous other kidney advocates who dedicated time and effort to the needs of kidney patients across the U.S. AAKP's mission remains to improve the lives of fellow kidney patients and their families by helping them deal with the physical, economic and social impact of kidney disease.

**"Why is public policy important to kidney patients? Because OUR LIVES depend on it!"**

AAKP believes the informed patient is the best advocate! AAKP provides fellow kidney patients with the necessary tools and information to be effective advocates.

AAKP actively addresses public policy with government officials, including Congress and Federal agencies, such as the Centers for Medicare and Medicaid Services (CMS).

### **AAKP's Policy Priorities**

While there are a number of important national healthcare issues, AAKP currently focuses its efforts on four public policy issues.

1. Improving the quality of care for kidney patients.
2. Ensuring that home dialysis is an option as a regular standard of care.
3. Extending coverage of immunosuppressive drugs.
4. Increasing the number of organ donations.

## The Statistics

According to research compiled by the ESRD Network Forum, at the end of 2004 there were 321,539 patients being dialyzed of which 104,056 were new (incident) ESRD patients.

The ESRD Network research also shows the pediatric population is the smallest ESRD population, with 1.1 percent of the ESRD new population under 20 years old. Almost half (46.6 percent) of the new patients in 2004 were between the ages of 60 and 79.

While the majority of the dialysis patients are white, African Americans and Native Americans comprise a disproportionate high number of ESRD patients. African Americans make up 12 percent of the national population, but make up 36.4 percent of the total dialysis prevalent population. The research shows males represented over half of the ESRD incident (52.6 percent) in 2004 and prevalent (51.9 percent) population.

The annual mortality for patients on dialysis in the United States is about 24 percent, much higher than the mortality rates in Europe and Japan.

## Why Should You Advocate?

The easy answer to the question is we know advocacy works. When constituents speak, lawmakers listen. However, being an advocate requires us to be specific. This is true across the board – from improved roadways and bridges, to better public schools, to treating diseases – the voice of advocacy needs to be unified in order for the message to be heard. Lawmakers need to hear from you. They need to know

exactly what it is you need from them before they will take action.

The documents that founded our country relied – and continue to rely – on one critical principle: a true democracy requires citizen participation in order to effectively serve its people. As Americans, each of us must participate in our democracy if our country is to continue as a free and bountiful society.

AAKP encourages kidney patients to directly contact their Senators and Representatives in the U.S. Congress. Patients have both the right and responsibility to make their voices heard in Congress and elsewhere in government.

## Making Contact

### *Tips on Writing Your*

### *Congressional Representative:*



The most popular way of contacting a lawmaker is through a letter. Here are some helpful suggestions:

- 1. State your purpose for writing the letter in the first paragraph.** If you are contacting the Representative in regard to a specific piece of legislation, identify the bill and its number. Example: House Bill: H.R. 9898, Senate Bill: S. 123.
- 2. Be courteous.**
- 3. Briefly share the story of your kidney patient experience.**
- 4. Get straight to the point and address one issue in each letter.** Also, try to keep the letter to one page.

Constituent concerns are important to members of Congress – and this letter lets

your members of Congress know what is important to you! AAKP would appreciate a copy of any letter you send to Congress.

### *Tips for Visiting Your Congressional Representative:*



#### **1. Plan your visit carefully**

Do you want a meeting in the Washington, D.C., office or the local district office? Determine what you want to achieve and exactly with whom you want to meet. Who is the best person to meet with to accomplish your goal?

#### **2. Make an appointment**

Call your Representative's office and ask to speak with the appointment secretary or scheduler. Explain the reason for your visit. It is easier for congressional staff to arrange a meeting if they know what you wish to discuss and your relationship to the area or interests represented by the Congressman or Senator.

#### **3. Arrive on time and with patience**

Get to the appointment on time and be prepared to wait. It is not uncommon for a Congressman to be late for an appointment because of a prior engagement.

#### **4. Be prepared**

Do your research and bring it with you to the meeting. Make talking points. This way, you know exactly what to say. Also have examples that demonstrate the benefits associated with siding with your cause.

#### **5. Be political**

Politicians want what is best for the constituents in their district or state.

Make a clear connection between your issues and the politician's constituents.

#### **6. Thank you**

Follow up the meeting with a thank you letter outlining the different points covered during the meeting. Enclose any additional requested information or materials.



#### *Contact by Phone:*

Call the U.S. Capitol Switchboard to get your Senator or Representative's office telephone number. The number to the switchboard is (202) 224-3121. To call a Congressman or Senator's local office, check your local phone directory.

#### **1. Telephone calls are often answered by a staff member, not the member of Congress.**

Ask to speak with the caseworker who handles healthcare issues.

#### **2. Once someone answers the phone, identify yourself.**

Tell the aide you want to leave a message. Example: "Please tell Senator/Representative (Name) that I support/oppose (S.123/H.R.9898)." You can also comment on an issue and state what action you want taken on that particular issue.

#### **3. Make sure you speak clearly.**

State the reasons for your support or opposition to the bill. Let the listener know how the bill affects you and your family. Request a written response to your telephone call.

Another way to find your local Congressman is to log on to [www.house.gov](http://www.house.gov). To find your Senator, log on to [www.senate.gov](http://www.senate.gov).

## Who's Who?

How do you find out who's who, now that you have decided to reach out to your Congressional Member?

Congressional Members have at least two offices: one in the district or state and one in Washington, D.C. House Members usually have one or two district offices. Senators usually have between two to five offices, usually in larger cities within the state. Each office has a number of staff people with various responsibilities. Below is a brief rundown of the roles and titles of key staff members. In communicating with the office, it will help you to know who supports your Congressman and Senator, and who among the staff is the most appropriate to help you with your issue.

### District and State Staff


- **Caseworkers:** If you want help on a problem concerning federal agencies, ask for a caseworker who handles that issue (the healthcare caseworker, for example, if you wish to discuss kidney disease). District or state caseworkers are masters at maneuvering through the maze of the federal bureaucracy – it is what they do for you.
- **District/State Scheduler:** If you want to meet with the Representative or Senator in the district or state, or if you want to invite him or her to an event, ask to speak with the district or state scheduler. This individual schedules the Member's time when he or she is in the district or state. Remember, some offices may not have a person who performs this function, in which case you will be referred,

most likely, to the scheduler in the Washington, D.C. office.

- **Field Representative:** If you want to meet with a district staff person to discuss a particular local issue, or if you want to invite someone from the district staff to a local event or meeting, ask for the field representative who handles your issue. Field representatives can also talk with you about federal issues directly affecting the district or actions of a federal agency on something that affects a local group of people or a community.
- **District/State Office Director:** This person oversees the operations of the district or state staff. He is often the point person in the district office for highly sensitive local political issues. Constituents should ask for this person if they feel their concerns are not being met by others in the office.

### Washington, D.C. Staff

- **Staff Assistant:** Most House offices have at least one staff assistant. Most Senate offices have at least two. They handle the front desk duties, which include answering the phones, greeting visitors, sorting mail, coordinating tours and other administrative tasks.
- **D.C. Scheduler/Executive Assistant:** If you are going to be in Washington, D.C. and want to meet your Representative or Senator, contact the D.C. scheduler (sometimes called the Executive Assistant). Do not be surprised if your Representative or Senator does not meet with you



personally. As you can imagine, Members are extremely busy and meeting with the right staff person can be equally effective, maybe more so.

- **Legislative Assistant (LA):** If you want to talk, either in person or on the phone, about a particular policy issue, ask for the legislative assistant who handles that issue. Legislative assistants handle the bulk of the policy work in a Congressional office. A House office usually will have two to four legislative assistants and a Senate office will have twice as many. There is generally a legislative assistant responsible for healthcare issues.
- **Legislative Director (LD):** In some cases, the person who handles your issue may be the legislative director. The legislative director handles policy issues and oversees the legislative staff. There is usually one legislative director in each Congressional office.
- **Legislative Correspondent (LC):** You may also be referred to a legislative correspondent, who in addition to drafting letters in response to constituents' comments and questions, generally handles a few legislative issues. Most House offices have one or two legislative correspondents. Senators have three to five, depending on the size of their state's population.
- **Press Secretary/Spokesperson/Communications Director:** If you want to include something about the Representative or Senator's view in a newsletter, or have questions related

to the press operations of the office, ask for the press secretary.

### Get Involved

No matter how you choose to contact your Representatives in Washington, D.C., let your Representatives know you want them to support bills ensuring you are receiving the best possible healthcare. Do not be afraid to voice your opinion, whether you agree with a policy or not. Lawmakers rely on public opinion to make their decisions. Your actions **CAN** have a positive effect on your healthcare and the millions of others in this country who have kidney disease.

A small group of concerned citizens has the power to change the world. If you are passionate about an issue, it is your right – and your obligation – to become involved with your government to advocate for (or against) that issue. Our system of government works best when we all participate. Being an advocate means being dedicated to making a difference.

Please join AAKP, encourage fellow patients to join AAKP, and let us speak with one strong, proud **PATIENT** voice. AAKP believes public policy opportunities have never been greater and we must all participate.

Sign up for AAKP's **FREE** monthly electronic newsletter, *AAKP Public Policy Briefing*, to learn more about public policy and government issues affecting kidney patients. Interested subscribers can join the mailing list by sending an email to [info@aakp.org](mailto:info@aakp.org), or by calling 800-749-AAKP.

# AAKP Membership

AAKP IS THE ONLY NATIONAL ORGANIZATION DIRECTED BY KIDNEY PATIENTS FOR KIDNEY PATIENTS.

## Benefits of Membership:

- A membership packet filled with some of our most popular publications and your very own member ID card.
- Subscriptions to AAKP's magazines: *aakpRENALIFE* and *Kidney Beginnings: The Magazine*.
- Opportunity to subscribe to AAKP's five FREE electronic newsletters.
- Access to **AAKP My Health™** (an online resource for patients who want to be more proactive in managing their healthcare).
- Automatic membership in the AAKP local chapter nearest you (where applicable).
- Advanced updates of upcoming programs and events.
- Access to relevant and updated public policy information.
- Affiliation with an organization that shares your commitment to making a difference.
- Assurance that your voice is heard and your interests are represented in Washington, DC.

## 3 Easy Ways to Become a Member...

1. Web site: Visit the Membership section of our Web site, [www.aakp.org](http://www.aakp.org), to join instantly.
2. Mail: Complete the membership application below and mail it to us at the address on the bottom of the application.
3. Phone: Give us a call at (800)749-AAKP.

Please allow 4 to 6 weeks to receive your membership packet.



## Membership Application

I am not interested in membership at this time, but please send me a complimentary package of information.

I am already a member of AAKP but I would like to make a donation of \$\_\_\_\_\_.

### Member Information

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_

ZIP: \_\_\_\_\_ Phone: ( ) \_\_\_\_\_

Email: \_\_\_\_\_

### Choose a Membership Category:

- Patient/Family Member.....\$25/annually
- Professional Member.....\$45/annually
- Physician Member.....\$100/annually
- Institutional Member..... \$200/annually
- Life Member..... \$1,000\*

\*or four payments of \$250 every six months for two years

### Payment Method

- Check (enclosed and payable to AAKP)
- Visa  American Express
- MasterCard  Discover

Account number: \_\_\_\_\_

Name on Card: \_\_\_\_\_

3 or 4-Digit Security Code: \_\_\_\_\_

Expiration Date: \_\_\_\_\_

Mail completed form & payment to: American Association of Kidney Patients, 3505 E. Frontage Rd, Ste. 315, Tampa, FL 33607

[www.aakp.org](http://www.aakp.org)

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