



# REACH OUT TO YOUR REPRESENTATIVES

## Building Advocacy Partnerships

### The Importance of Advocacy Partnerships

Public policy has become an area of increased focus by patients and those affected by kidney disease at both state and national levels. As you all know, we have in the last few years participated in the discussion surrounding new regulations, such as the ESRD Program Conditions for Coverage, and new laws such as the Medicare Improvements for Patients and Providers Act, and the bundling of dialysis services, now entering its implementation phase, along with the new Health Care Reform Act, which has impact on the care of dialysis patients.

At the state level we have been part of increasing Medigap access, ensuring nutritional supplements and transportation for patients and considering new and innovative ways to address the organ donor shortage, such as living donor registries.

**These accomplishments didn't just happen. To a large extent, they were the result of positive relationships between individuals in the renal community – particularly those educated and involved patients -- and key legislators.**

Successful advocacy relationships sometimes develop as an issue gains momentum in state houses or in Congress, and the chair of a key committee adopts it as a priority and begins working closely with its proponents. But, more often, the relationship predates the issue. The legislator understands how an evolving initiative relates to his or her district's needs and the desires of their constituents, to local organizations and ongoing projects and, importantly, to the interests of the legislator's chief supporters. Therefore, it is very much in the long-term interest of patients to develop positive relationships and effective communications with legislators once they are in office. **In this way, the kidney community through its most affected members can build advocacy partnerships that will help make tremendous gains in enlightened public policy and public funding for quality renal care.**

### Reaching Out to Legislators

Let's talk about our plan for reaching out. We want to start now, and lead up to District visits during the August 2010 recess. Do you know who your state and national legislators are? Or, more important, do they know who YOU are? Depending on the size of your community or focus area, one or more state Representatives (or Assembly members) and one or more state

Senators represent you at your state's capital, where critical decisions regarding funding for programs are made. You are also represented by at least one U.S. Representative and two U.S. Senators. Here's how to begin building advocacy partnerships with them.

## Locate your Legislators

- For your federal representatives, all you need is your zip code and your street address. Go to the link here for [GovTrack.us](http://www.govtrack.us), a website for a civic project to track Congress, which will bring you to their search page for members of Congress: <http://www.govtrack.us/congress/findyourreps.xpd>. Enter your zip code and street address or zip code+4, and it will bring up a map of your region and list your two Senators and your House Representative. Each listing provided is a hyperlink to a wealth of information on each legislator: biography, contact info, voting records, committee memberships, bill sponsorship, and campaign contributions as well as a connection to their official websites. You can even click on an option to provide you with ongoing tracking via emails for each of them, as you'd like.
- For information on state legislators in addition to federal representatives, [Congress.org](http://www.congress.org) is a nonpartisan news and information website devoted to encouraging civic participation. Use either of the following links with your zip code to access information on all your legislators: <http://www.congress.org/congressorg/dbq/officials/?lvl=L> or <http://www.congress.org/congressorg/directory/congdir.tt>
- **Start with a letter.** Write each of your legislators a short personal letter introducing yourself and RSN. Your unique perspective on living well with kidney disease is what they need. Enclose a brochure, news clipping, resource list, press release, or other information—the more you can offer the better. Your letter will be read by staff and perhaps by the legislator, too, depending on how busy he or she is. You will almost certainly receive a reply.
- **Reach out to district office staff.** All national legislators and most state legislators maintain district offices. Make a point of introducing yourself to the staff directors for your area. Arrange for them to perhaps visit your dialysis or transplant facility. Follow up with notes and phone calls. Develop an ongoing cordial relationship. These individuals may become some of your most important allies.
- **Establish relationships with key staff.** Find out who on the legislator's staff works on issues related to health care. Write to this person as well. He or she will likely have seen what you sent to the legislator, but will appreciate the personal contact.
- **Build on existing relationships.** Do you have any ongoing connections with legislators and/or their staff? If so, ask them to serve as key contacts for you, even if their committee membership is outside of the usual renal realm.
- **Keep in touch.** Add legislators to your mailing list for newsletters, press releases, and other communications and announcements. If possible, avoid adding them to lists that are used to solicit donations. It enhances the communication when you add a brief personal note conveying how much you appreciate the legislator's interest in your work.

- **Send thank-you notes.** Legislators are human—they like to be appreciated. Get into the habit of thanking your legislators for introducing and supporting legislation and budget measures that further the cause of quality renal care.
- **Casual personal connections.** Be open to connecting with legislators at community events and public hearings and to chat about renal issues. This works especially well if they can combine it with a message of positive feedback, such as “I want to thank you for your support of the Out of Network Coverage bill,” or “Thank you for co-sponsoring the bill that increases tax incentives for organ donation.” These contacts help foster the impression that you know about and appreciate what the legislator is doing.

So what issues are we focused on this year? Even with all the legislative and regulatory change of the last year or so, considerable work still remains.

**Medigap access** - Currently, 31 states (with South Carolina and Georgia having most recently passed the laws, and the Tennessee State House moving it through channels for a floor vote) provide for access to Medigap policies for those individuals on Medicare under the age of 65, which includes many ESRD patients. The states where access is still not available are the following:

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|------------|----------------|-----------------|
| ◆ Alabama  | ◆ Montana      | ◆ Utah          |
| ◆ Alaska   | ◆ Nebraska     | ◆ Vermont       |
| ◆ Arizona  | ◆ Nevada       | ◆ Virginia      |
| ◆ Arkansas | ◆ New Mexico   | ◆ West Virginia |
| ◆ Idaho    | ◆ North Dakota | ◆ Wyoming       |
| ◆ Indiana  | ◆ Ohio         |                 |
| ◆ Iowa     | ◆ Rhode Island |                 |

During the last session of Congress, a bill was introduced to federally mandate Medigap access equally across the country, but that was not among the provisions of the Health care reform act and has not been re-introduced thus far this session. So this is an issue we are working on one state at a time.

**Organ Donor Shortage:** With the current wait list for organ candidates standing at 107,307 for all organs, and 84,742 of those waiting for kidneys, our current system of encouraging donation is falling far short of the need. Some states are looking at living donor registries, others at electronic signature sign-up, while presumed “opt-out” proposals have been introduced in still others. We need a unifying voice of how to address this shortage as the United Network for Organ Sharing looks at and re-evaluates its organ allocation policies.

**Immunosuppressives:** Considering the shortage of donor organs, once a transplant is received, it is crucial that it be maintained properly with an immunosuppressives regimen. Access to these drugs currently is covered only for 3 years post transplant, at which time many patients are hard pressed to find alternative coverage or pay out of pocket costs. With the health care reform law, and greater availability of insurance coverage to all individuals, this problem may be reduced, but without specific provisions for that coverage, there are no guarantees.

**Quality Issues in Dialysis:** With the final rule on the CMS Proposed Prospective Payment System (PPS) due out shortly, the next items in the revision of the way in which dialysis care is provided and paid for are quality measures. Especially in light of some of the changes being made to the way medications are provided and lab tests are done, a thorough and considered quality metric system is essential to ensure patient quality care and safety. Currently being reviewed are measures including Anemia Management, Dialysis Adequacy, Bone and Mineral Metabolism Management, Fluid Management and Infection Control Measures. It is critical that the patient's perspective is understood in these very important developments.

**Congressional Kidney Caucus:** This is a reinvigorated coalition of House representatives who have an expressed interest in renal issues. Under the leadership of Reps. Mark Kirk (R-IL), Jim McDermott (D-WA), Jesse Jackson (D-IL) and Mike Conaway (R-TX), new members are being encouraged to join, and this is an easy ask for any federal legislator. We are looking to expand this to Senate membership as well.

We have attached separate flyers on each of these issues for you to use in presenting to your legislators, with an outline of why each of them is important in supporting the kidney community.

So what do we want you to do? Start now. Using the ideas listed above, begin to make those connections with your legislators to develop relationships if you haven't done so before. Once you have identified your legislators, you can make those initial contacts. Aim for the ultimate goal of a personal meeting when your federal legislators are in their home districts during the August recess, and your state legislators are on their home turf as well. With no agenda except good quality care and a full and healthy life for ourselves and others affected by renal disease, patients and their perspectives are very welcome in the legislative process.

