

Stroke Advocacy Network

Advocacy Tool Kit

for Stroke Advocacy Network members

July 2014



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EXECUTIVE SUMMARY

The **Stroke Advocacy Network** begins with you. Thank you for being a stroke advocate—making your voice heard, telling your story and taking action to influence public policies involving stroke. This tool kit provides you with tools and information to connect with your legislators while they're at home in their district.

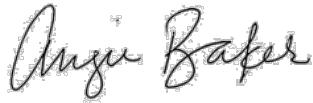
Local visits and meetings are the single best way to help legislators understand how policy issues and the legislation they work on impacts people like you (their constituents). These types of meetings are easy to attend and arrange.

This tool kit provides information about connecting with your legislators in three ways:

1. **Attend a town hall meeting**—This is an event the legislator schedules to meet and greet constituents.
2. **Meet at a legislator's local office**—Every legislator has at least one office location in the district where they meet with constituents, people representing interest groups and others.
3. **Host a site visit**—A site visit is when you invite a legislator to see something in the district.

Keep in mind that a **National Stroke Association** staff member is always available to help you take these actions and answer questions. You are the **Stroke Advocacy Network**—it's your voice that will make a difference for the stroke community!

Sincerely,



Angie Baker
Manager, Policy Advocacy

WAYS TO CONNECT WITH LEGISLATORS

While legislators spend time debating and voting on bills, they also spend a significant amount of time talking to people like you, their constituents. Knowing what's going on in the district allows them to better understand how their votes impact the people they were elected to represent.

The best time to connect with legislators is while they're at home in their districts. At the state level, these time periods are often referred to as when state legislatures are "out of session." In contrast, Congress typically calls them "district work periods."

There are three easy ways to connect with your legislators while they're at home:

- Attend a town hall meeting
- Meet in a legislator's district office
- Invite a legislator to visit something in the district.

This tool kit describes how you can become involved in each of these opportunities—to help ensure that your legislators understand stroke-related policies. The more they know, the better they'll understand what policies will support the needs and challenges faced by all segments of the stroke community.

Option 1—Attend a Town Hall Meeting

One of the most effective ways to gain the attention of a legislator or their staff is to attend a town hall meeting (also called community meeting). Legislators arrange these meetings to let people know what they're working on and to listen to what people think about those and other issues.

Town hall meetings are open to the public and are generally held at large community facilities, such as schools, community centers or other public gathering places. State legislators usually schedule town hall meetings when they're out of session. Members of Congress typically schedule them during district work periods.

The easiest way to find out about meetings being held by your legislators is to call their nearest local office. State legislators typically have one office (in the state capital). Members of Congress have an office in Washington, D.C., and at least one office in their district. Senators and representatives from larger districts may have multiple offices (typically located in the most populous communities in the district). You can find contact information for your state legislators and members of Congress through the **Stroke Advocacy Network** website at <http://www.stroke.org/stroke-resources/resource-library/advocacy-tool-kit>.

If you attend a town hall meeting, please let the **Stroke Advocacy Network** know what the legislator had to say about stroke-related issues. You can reach us at advocacy@stroke.org or 1-800-STROKES.

What to Do Before the Meeting

Before you attend a town hall meeting, take a moment to learn a little about the legislator hosting the event. You can find this information on your legislator's individual webpage. Find his or her webpage with the help of the **Stroke Advocacy Network** at <http://www.stroke.org/stroke-resources/resource-library/advocacy-tool-kit>.

Learning more about the legislator can tell you how much he or she may already know about healthcare issues, including stroke. That way, you can tailor your question or message based on his or her familiarity with your issue. Some of the information that's good to know is:

- The legislator's occupation (current and/or previous);
- What bills he or she has introduced;
- What committees he or she serves on; and
- What type of district he or she represents (all urban, all rural, combination, etc.).

What Happens During the Meeting

Although the format varies, usually the legislator makes some opening remarks and introduces his or her staff. There may also be other local leaders in attendance who wish to make opening remarks. Then, the floor is opened up to comments from the audience.

You'll only have a minute or two to ask your question or make your statement. Please respect that time restriction. Legislators are interested in giving as many people as possible a chance to speak and that can only happen if everyone keeps their remarks short and to the point. It might help to write down your question or statement before or during the meeting to help you organize your thoughts and get to your point quickly.

Also remember that legislators (and their staff) respond better to positive comments. If you're stating a problem, ask them how they would solve it or provide a suggestion of your own. Ultimately, problems get solved by people who understand the problem and work together to come up with a solution!

Managing Questions and/or Reactions to Your Remarks

Legislators commonly give certain responses at town hall meetings. We've noted a couple here and indicate how you should respond to help ensure that your legislator takes action on your request after the meeting.

"Sounds great! I'll support (or sign on to) that."

Thank your legislator and let him or her know you'll be in touch to work out the details. If possible, find out the names of the local and Washington, D.C., staff responsible for that issue. Follow up with those people after the meeting to make sure the legislator takes the action promised. Sometimes legislators agree to take specific actions but forget if not prompted. You can also let the **Stroke Advocacy Network**

team know about any commitments you receive from legislators. We can help by following up with those legislators as well.

“Sounds interesting, I’d like to learn more.”

Legislators are often unwilling to make commitments the first couple of times they are asked. This is especially true of newly elected legislators. This is in part because they simply cannot agree to everything that is asked of them and are eager to learn more about an issue before making a decision. If you get this reaction, thank your legislator and let him or her know you’re happy to serve as a resource. Find out the name of the appropriate legislative staff members and follow-up with them. Also, let the **Stroke Advocacy Network** team know of their interest so we can support your follow-up efforts if needed.

Other Meeting Tips

Remove the phrase “I only met with staff” from your vocabulary. Talking to a staff member is, in many ways, more effective than talking to a legislator. Staff members can take more time to understand specific issues and how those issues impact people. They also “have the ear” of the legislator. Legislators speak with their staff daily. Turning a staff person into a champion for your issue is an effective advocacy strategy.

If you want to talk to your legislator, but you don’t want to ask a question during the meeting, think about arriving early or staying after the meeting concludes. Many times legislators and their staff are willing to have one-on-one discussions with constituents. Just remember to have your question(s) or request(s) ready before you start a discussion. Often, you’ll have even less time with the legislator or their staff in a one-on-one discussion than you would during the meeting.

What You Should Talk About

Should you decide to attend a town hall meeting, you’ll want to talk about issues that are important to you. The **Stroke Advocacy Network** can help you identify stroke-related issues pending before Congress or in your state capitol.

If you’re interested in meeting with your state legislators, you can visit the **Stroke Advocacy Network’s** State Advocacy Action Center at <http://www.stroke.org/get-involved/advocate/state-issues> to find out what stroke-related issues are pending in your state legislature. You can also contact a **National Stroke Association** staff member for this information at advocacy@stroke.org or 1-800-STROKES.

Option 2—Meet in a Legislator’s Local Office

Every legislator has a local office where he or she is available to meet with his or her constituents. And remember, you don’t always have to meet with the legislator. Staff members are available for meetings as well. If you have friends or colleagues who share the same views on the issues you want to discuss with your legislator, consider inviting them to join you at the meeting.

Make an Appointment

Typically, you have to make an appointment to meet with a legislator or his or her staff. To get a meeting with a staff member, just call the legislator’s office and request the meeting. If you don’t know which staff member you should meet with, tell the office you would like to meet with the staff person who handles healthcare issues.

If you want to meet with the legislator, you usually have to send the office a written request. See Appendix A for a sample, or template, you can use to make this request. For state legislators, you can generally send this request directly to the legislator. For member of Congress, address the correspondence to the “scheduler” or “healthcare legislative aide.” It’s a good idea to contact the office first to see how they would like you to make your request. You can find the phone number to your legislator’s nearest office on the **Stroke Advocacy Network** website at www.stroke.org/find_legislator. Also, make sure to include as much information about the meeting as you can, including the:

- Topic of the meeting (i.e., healthcare issues related to stroke);
- Names of everyone who will be attending with you (if any); and
- Bill numbers of the legislation you will be speaking about (if relevant).

After you send your initial message, follow up with the office by phone. Sometimes it takes a “nudge” to get your request to the top of the pile and a phone call is the perfect way to do that.

During the Meeting

You have an appointment—now what? Here’s a good way to approach the discussion you’ll have with your legislator or his or her staff during the meeting:

- **State who you are and make the district connection**—For example, “My name is [your name], and I live in [town]. I’m a member of National Stroke Association’s Stroke Advocacy Network, and I’m a [stroke survivor, caregiver of a stroke survivor, healthcare professional who cares for stroke patients, etc.]”
- **Tell your story**—Remember that you’ll only have so much time for the meeting. That means you might want to think before the meeting about how you’ll tell your story. You can find it in Appendix B.

- **Explain why you're there (make your "ask")**—For example, "I'm hoping that you [or the legislator if you're meeting with staff] will support [bill number], which would help the stroke community by..."
- **Explain why it's important to you**—This is where your personal story comes back into the discussion. For example, "[Bill number] is important to me because [how making that change would help you or someone you know]."
- **Leave behind materials**—If you brought materials to leave behind for the legislator or staff (which is suggested, but not necessary), feel free to refer to them if you need to. However, don't read them to the person you're meeting with.
- **Be a resource**—Legislators and their staff can't possibly know everything about every issue that crosses their desks. They need people in their district whom they can call when they want to understand an issue better or determine how a potential policy change affects people. Let them know you're available to be a resource on stroke-related issues. Be sure to leave your name and contact information with the person you meet with, and ask for his or her business card.

Also, while it's common for legislators and their staff to wear suits or business attire during these meetings, you don't have to. If you have that clothing in your wardrobe already, wear it. But if you don't, just go to the meeting in something presentable. Your ideas, experiences and expertise are the focus of the meeting—not what you're wearing.

Follow Up

There are a number of reasons to follow up with your legislator's office after your meeting. If the legislator asked for additional information or asked a question you couldn't answer during the meeting, make sure you get that information to his or her office right away.

Legislators are asked for things every day. However, you might be surprised at how infrequently they're thanked for their efforts. Send a note to the legislator thanking him or her for their time and attention to your issue. Remember to also send a note or email to any staff members you met with as well. This is a great way to keep your meeting and your issue on their radar.

Remember to maintain regular contact with the legislator and his or her staff after your meeting. One easy way to do this is by following the legislator on Facebook, Twitter or other social media sites. In many cases, legislators send information about their activities to constituents by email. You can sign up for these opportunities on the legislator's website.

Option 3—Host a Site Visit

A "site visit" is an in-person visit by a legislator (or a staff member) to a facility or group in the legislator's district. These visits are an invaluable way to educate legislators and their staff about the impact of stroke-related policy issues on their constituents. Also, it's one of the best ways to capture

their attention. You can invite them to visit a stroke support group, take a tour of a hospital, attend a community health fair or participate in an event, such as a walk or run to benefit stroke.

The following information will give you a good sense of what hosting a site visit entails and how to organize it. Keep in mind that **Stroke Advocacy Network** staff can help you plan and organize your site visit. Please contact advocacy@stroke.org or 1-800-STROKES for assistance.

You can identify your legislators (state and federal) using the **Stroke Advocacy Network** website at <http://www.stroke.org/stroke-resources/resource-library/advocacy-tool-kit>.

Best Time to Schedule a Site Visit

Remember that state legislators and members of Congress have legislative responsibilities that require them to be in the state capital (state legislators) or in Washington, D.C. (members of Congress) during certain weeks of the year. This means they won't always be available to participate in a site visit.

The easiest way to find out if your legislators are available to participate in a site visit is to call their nearest local office. State legislators typically have one office (in the state capital). Members of Congress have an office in Washington, D.C., and at least one office in their district. Senators and representatives from larger districts may have multiple offices (typically located in the most populous communities in the district). You can find contact information for the offices of your state legislators and members of Congress through the **Stroke Advocacy Network** website at <http://www.stroke.org/stroke-resources/resource-library/advocacy-tool-kit>.

Role of Legislative Staff

If a legislator can't participate in a site visit, then invite his or her local staff to participate. This is an effective advocacy tool. Legislators depend on their staffs to provide them with the type of information you would provide during a site visit. Think of legislative staff as an extension of the legislator in these situations.

It may actually benefit you to invite a legislative staff member on a site visit before you invite his or her boss. That way, assuming you make the visit as interesting as possible, you can turn the staff person into an advocate for future visits. Legislators often make decisions about where they might spend their time based on a positive experience their staff person had.

Decide What to Showcase

What do you want to show the legislator? If you're inviting them to your stroke support group, you might just want to let the legislator listen to members of the group talk about their stroke and the day-to-day challenges they face. If you can, link your stories and discussions to changes in healthcare policies that could lessen those challenges. The **Stroke Advocacy Network** can help you identify that legislation. Visit our website to view stroke-related legislation pending in Congress (<http://www.stroke.org/get-involved/federal-issues>) or in your state (<http://www.stroke.org/get-involved/advocate/state-issues>)

If you work at a stroke center hospital or a stroke rehabilitation center, consider inviting the legislator to tour your facility. These types of meetings raise awareness about stroke, highlight the facility’s additional stroke training and give legislators valuable insights into the needs of all aspects of the stroke community—stroke patients, survivors, caregivers, family members and the healthcare professionals who interact with them.

Decide Who to Invite

State legislators don’t always have staff assigned solely to them. Therefore, they’re more likely to attend a meeting with a constituent or a site visit. Members of Congress have “district staff” in their local office(s) and “DC staff” in Washington, D.C. Who should you invite to a site visit? Always invite the district staff. However, if the topic of the site visit includes issues that are the subject of pending legislation, then it would be useful to invite the D.C. staff as well.

Also, think about including the entire continuum of people affected by your issue in the event. For example, if your site visit includes a tour of a rehabilitation facility, schedule time for the legislator or staff to speak with patients, caregivers, family members, healthcare providers and facility administrators. That way, the legislator gets a complete understanding of how important that facility is to the entire stroke community.

If you intend on inviting representatives from media outlets, be sure to tell the legislator and his or her staff when you invite them.

Invite the Legislator or Staff

Members of Congress and some state legislators will require you to put your invitation in writing. See Appendix C for a sample template you can use to ask your legislator or his or her staff to participate in your site visit.

For state legislators, you can generally send this request directly to the legislator. For members of Congress, you should address the correspondence to the “scheduler” or “healthcare legislative aide.” It’s a good idea to contact the office first to see how they would like you to make your request. Also, be sure to provide as much information as you can, including:

- Where the site visit is taking place;
- The topic of the visit;
- Who the legislator will be meeting with during the visit (e.g., stroke survivors, doctors, etc.);
- If other elected officials will be attending;
- If the media has been invited;
- Approximately how long the visit will last; and
- Any other information you feel the legislator should know.

After you send your initial message, follow up with the office by phone. Sometimes it takes a “nudge” to get your request to the top of the pile, and a phone call is the perfect way to do that.

Plan for the Site Visit

For any site visit, you'll have to organize the logistics of the event. This includes developing an agenda. The agenda should be as specific as possible and you should provide a copy to either the legislator's staff person or the legislator when he or she arrives or send it to his or her office prior to the event. This not only keeps the meeting organizer "on track" so the event runs smoothly, but it also allows the legislator and staff person to know what's happening next. See Appendix D for sample site visit plans.

Here are some other items and issues you'll want to plan for when organizing your site visit (all of these items apply to both legislator and staff participation):

- Check in with the legislator's office the day before the visit to remind him or her of the event and see if he or she has any last-minute questions.
- Review the agenda to make sure all times are reasonable and develop contingency plans if necessary.
- Make sure the legislator knows where to park and which entrance to use to access the meeting space.
- Prepare for all types of weather if it's an outdoor location.
- Prepare a handout that the legislator can take back to his or her office. It should summarize the most important points you want him or her to learn during the visit.
- Assign someone to take pictures, video or notes during the site visit. If asked, let the legislator know what those items might be used for after the meeting.
- Be respectful of the legislator's time and end the event at the originally scheduled time.

Follow Up

There are a number of reasons to follow up with your legislator's office after the site visit. If the legislator asked for additional information or asked a question you couldn't answer during the visit, make sure you get that information to his or her office right away.

Legislators are asked for things every day. However, you might be surprised at how infrequently they're thanked for their efforts. Send a note to the legislator thanking him or her for their time and attention to your issue. Remember to also send a note or email to the staff members who attended as well. This is a great way to keep your site visit and your issue on their radar. Think about including photos from the site visit with your thank you note. Legislators can use these photos on their website and social media sites.

Remember to maintain regular contact with the legislator and his or her staff after the visit. One easy way to do this is by following the legislator on Facebook, Twitter or other social media sites. In many cases, legislators send information about their activities to constituents by email. You can sign up for these opportunities on the legislator's website.

APPENDIX A: Meeting Request Template

Use this template for an email or letter to send a message to your legislator requesting a face-to-face meeting. If you're sending a letter, remember to add the date and the legislator's address before this information. For members of Congress, include "Attn: Scheduler or Healthcare Aide" to the address.

Dear [Representative/Senator Last Name of the Legislator],

As a representative of [stroke survivors, caregivers, healthcare professionals who care for stroke patients, etc.] in your district, I'm writing to ask to meet with you in your district office during the week of [date]. I'm very interested in programs designed to help and support the stroke community. I'm specifically interested in talking to you about [describe the issue and add bill numbers if applicable].

This is critically important because anyone can have a stroke. In the U.S., about 795,000 people will have a stroke this year, averaging one every 40 seconds. While stroke is the fourth leading cause of death, it is also a leading cause of long-term disability. There are currently 7 million stroke survivors in the U.S. living with the challenges of life after a stroke. Stroke affects not only individuals and their loved ones, but also the entire healthcare system, costing an estimated \$73.7 billion in direct and indirect costs in 2010.

There are many stroke survivors and caregivers in your district. I hope you'll be willing to meet with me to discuss the challenges they face and how Congress can take action to reduce those obstacles.

To set up a meeting please contact [your name] at [your phone number] or [your email address]. I'll contact you in the next few days to see what may be possible.

Thank you,

[Your name]

APPENDIX B: Developing and Sharing Your Personal Story

The most important thing to remember in developing and delivering a message to your legislator is that you have something valuable to contribute. In fact, you are one of the most important people the legislator and his or her staff person will see that day.

Why? Because you are a constituent or you represent the concerns of constituents. Your job as an advocate is not to simply relay as many facts and figures about stroke as you can. Rather, your job is to make stroke and its effects real for the legislator or staff person. You can achieve that goal by telling your personal story.

Remember that you only have a limited amount of time to convey this story to your legislator or his or her staff during a meeting. The worksheet below will help you develop a strong, concise personal story to share at the meeting.

Worksheet: Developing Your Personal Story

Take some time to think about the following questions. Once you answer them, weave your responses into a sincere and powerful story to share during your meeting.

1. Why is it important for you to advocate for stroke?
2. How has stroke impacted your health or the health of a loved one?
3. How has stroke impacted your finances and/or your ability to work?
4. How has stroke most profoundly impacted your life (for better or worse)?
5. What's the most important thing you want others to know about surviving a stroke?

APPENDIX C: Site Visit Request

Use this template for an email or letter requesting that a legislator or his or her staff participate in a site visit. If you're sending a letter, remember to add the date and the legislator's address before this information. For members of Congress, include "Attn: Scheduler or Healthcare Aide" to the address.

Dear [Representative/Senator Last Name]:

As a representative of the stroke community in your district, I'm writing to ask you to visit [describe the site or group you're asking the legislator to visit] in your district. We're very interested in programs and policies that impact the stroke community.

This is critically important not only to our community, but also to the nation as a whole. In the U.S.:

- About 795,000 people will have a stroke this year, averaging one every 40 seconds;
- Stroke is the fourth leading cause of death, killing about 137,000 people each year, which is one death every 4 minutes;
- There are 7 million adult stroke survivors;
- Stroke is a leading cause of serious, long-term disability; and
- The estimated direct and indirect cost of stroke was \$73.7 billion in 2010.

There are many people in your district who have been impacted by stroke, including stroke survivors, caregivers, family members and healthcare professionals who treat stroke patients. I hope you'll be willing to meet with us to discuss some of the ways the government can lessen the challenges faced by these groups.

Thank you for considering my request. To set up a meeting, please contact me at [your phone number] or [your email address]. I'll contact you in the next few days to see what may be possible.

Thank you,

[Your Name]

[Name of Your Facility or Group]

APPENDIX D: Sample Site Visit Plans

Here are some sample plans for a site visit. The specific details of your plan will depend on what you're showing the legislator during his or her visit.

Sample Site Visit Plan (Facility Tour)

(1.5-hour visit)

10 a.m. – 10:15 a.m. Greet the legislator and his or her staff as they arrive

10:15 a.m. – 10:45 a.m. Site tour (highlight stroke-related programs and services and the value they bring to patient care and recovery potential)

10:45 a.m. – 11:15 a.m. Meet with stroke patients, caregivers, medical staff, facility administrators, etc. (with snacks!)

11:15 a.m. – 11:30 a.m. Wrap-up and final questions and/or comments from the legislator or staff

Sample Site Visit Plan (Stroke Support Group)

(1.5-hour visit)

10 a.m. – 10:15 a.m. Greet the legislator and his or her staff as they arrive

10:15 a.m. – 11:15 a.m. Meet with members of the support group (share your stroke stories and ask the legislator or staff if they have any connection to stroke)

11:15 a.m. – 11:30 a.m. Wrap-up and final questions and/or comments from the legislator or staff