MS Advocacy Toolkit & Facilitation Guide for Self-Help Groups
Program Overview
This toolkit was designed to help you facilitate a Self-Help Group meeting with a focus on MS advocacy. By the end of the meeting, your group should understand why advocacy is important, how they can be engaged and what specific steps they can and will take to be MS activists!

MS activists are people who are dedicated to making a difference in the lives of people affected by multiple sclerosis. By introducing your Self-Help Group members to our MS advocacy program and talking candidly with them about activism - you are already making a difference. Thank YOU for being an MS activist!

Intended Audience
MS Self-Help Groups and other community groups and organizations.

Program Format
Presentation and discussion.

Time Considerations
- **Timeframe:** Any time or season.
- **Estimated presentation time:** 60-90 minutes.

Resources Needed
- **Space:** Any size meeting room.
- **Equipment:** No special equipment necessary.
- **Supplies:** Pens, Paper, Flipchart (not required, but you may want to use one.)
- **Handouts:** See “Materials Needed” on page 3.

This toolkit focuses primarily on legislative and community advocacy. The National MS Society also offers a toolkit and facilitator’s guide on Self Advocacy and Effective Communication. For more information about that toolkit, please reach out to your chapter staff liaison.
Program Logistics

Overview
This 60-90 minute workshop is designed to introduce Self-Help Groups and other community organizations and groups to the National MS Society’s advocacy program and train participants to be grassroots MS activists in their own communities.

Getting Started
Review the information in this guide, as well as any included materials, so you are prepared to answer questions as they arise.

Make sure you get a participant count before the workshop to ensure that you bring enough materials.

Materials Needed
Contact your state or chapter liaison for local and state specific advocacy information. You may want to research the local, state and federal representatives in your area, as this information will be helpful in your discussion.

You may wish to make copies of the “Tips of Successful Activism” section of this document for your Self-Help Group members.

Sign-up sheet for the Activist Network (included in this guide). Please make as many copies of the sign-up sheet as you need for your presentation. Return the completed pages to your chapter liaison by mail or email.
The following pages are a facilitation guide for your meeting. You may adapt this program to your presentation style and the particular needs of your audience.

**Meeting Agenda**

I. Welcome, introductions and definitions  
II. Why advocate?  
III. Making a difference – 10 simple ways to be an MS activist  
IV. Take action!  
V. Tips for successful activism  
VI. Conclusion
I. Welcome, introduction and definitions

Identify the three main goals for the presentation:
- To provide the group with information about advocacy and MS activism.
- To provide concrete suggestions for how they can get involved with our advocacy efforts.
- To develop a plan for how the group will take action.

Demystifying the word, “Advocacy”

“Never doubt that a small group of thoughtful, committed, citizens can change the world. Indeed, it is the only thing that ever has.” – Margaret Mead

Advocacy is speaking out – lending your voice to:
- Question policy
- Share your story
- Propose solutions

You may be one person with one voice but your story may be the catalyst that sparks a legislator to take action on an issue. Legislators often get their ideas for legislation from their own constituents. Furthermore, a legislator may need just 5 letters or calls from constituents about an issue to deem that is important and worthy of their consideration.

“To stay on the map you’ve got to keep showing up.” – Peter Gallagher

Advocacy is establishing a presence by:
- Building relationships with legislators and public officials by visiting, calling and writing to them often.
- Attending town halls and other community and legislative meetings.
- Educating your community about MS and the issues that affect people living with the disease.
“Everyone always says ‘I wish somebody would do something about that.’ It’s nice to be the somebody.” - John Driggers, MS Activist from Virginia

Advocacy is creating change:

- Being an MS activist gives you a chance to be the “somebody” and do something about the things everyone wishes would change. It gives you a chance to improve the quality of life for people living with MS in your community.

As advocates, we work on behalf of and with people living with multiple sclerosis to help facilitate necessary programs and services. For example, we help people navigate the Social Security Disability benefits program or we help people create accessibility for daily living in their communities. Some people might be health care advocates or patient advocates.

Activism is more than advocacy. As MS activists, we are individuals who are on the frontline — and we move together and speak with one clear voice to create legislative and regulatory changes that benefit people living with MS. That is MS activism.

Discussion Questions:
What other ways would you describe “advocacy?”
How are you already an activist in your own life or community?
II – Why advocate?

Advocacy makes a difference. Here are a few facts and stories about how Self-Help Groups and other MS Activist volunteers are creating change.

More than 2.1 million people across the world, live with multiple sclerosis. MS affects not only the individual diagnosed, but his or her friends and family as well. Advocacy helps to create awareness.

The West Chester Self-Help Group in Pennsylvania invited Karen Mariner, Vice-President of Advocacy for Pennsylvania and New Jersey, to one of their meetings at a local fitness facility. During the presentation, one of the members casually mentioned that State Senator Dinniman worked out at the facility. Karen suggested they invite him to speak at their group. They did and he enthusiastically said, “Yes.” After attending the meeting; getting to know the Self-Help Group members and learning more about MS, Senator Dinniman introduced the MS Awareness Week resolution in the Pennsylvania State Senate. Since then, the West Chester Self-Help Group has reached out to the Senator to discuss many policy issues, and he has supported every one. He even came to the local Walk MS for the first time this year and was escorted proudly by the group leaders. Most recently, Senator Dinniman invited the group to decorate his district office window for MS Awareness Week.
“Transportation and mobility play key roles in the struggle for civil rights and equal opportunity in the disability community. Affordable and reliable transportation allows people with disabilities access to important opportunities in education, employment, health care, housing, and community life.” – American Association of People with Disabilities

In April of 2013, the Charles County, Maryland Self-Help Group worked with the National Capital Chapter of the National MS Society to organize a program about the lack of dependable, accessible transportation in the region. In addition to securing the space, Self-Help Group members reached out to a local legislator, Delegate Peter Murphy, and invited him to attend. Also in attendance were staff from the county run transportation program, staff from VAN-GO, a private accessible transportation company, and a care manager who presented some local resources that are available to people living with MS. Together, the presenters and the 22 attendees were able to brainstorm about solutions to key issues that affect people with MS in the area. It was an excellent forum for people to listen and to be heard. As a result of the program and continued communication with MS activists, a relationship was formed with Delegate Murphy. He continues to be interested in advocating for people with MS at the state level.

Delegate Murphy speaking at the event.
Among people with MS, the most frequently cited reason for difficulty in access to prescription medication, MS medical care, and mental health care was cost. (Minden et al, 2007).

Early in 2013, a State Senator in Delaware drafted legislation that called for the elimination of co-insurance (when you pay a percentage of the cost of medication as opposed to a fixed co-pay). The bill also placed a monthly cap on the amount an insurer can charge a person for their specialty medications. The Senator asked the local chapter of the National MS Society to support the legislation as it made its way through the legislative process. The chapter enlisted the aid of their Government Relations Committee as well as all of the state’s Self-Help Groups and asked them to send emails and make phone calls to their legislators. In addition, several MS activists gave impactful testimony as the bill was discussed in committee. Quick action by MS activists and chapter staff generated a flurry of activity and support. The bill was passed unanimously by the Senate and then also passed by the House. It was signed into law on July 23, 2013. Due to the work of many individuals, including Self-Help Group members, the legislation was passed in just six months. This success illustrates the power of persistence and how working together can achieve great results.

Until the day when we have solutions for everyone affected by MS and prevention for future generations, MS activists strive to advance important MS issues that:

- Offer reasonable accommodations in the community for access and enjoyment.
- Maximize individual choice and independence for people who require long-term supports and services.
- Reduce distances to care providers and increase the number of providers.
- Increase investments in MS research.
- Eliminate barriers to affordable care and therapies that slow MS disease progression.

MS activism is active online and on the ground. The National MS Society works closely with legislators on both sides of the political aisle and with staff on Capitol Hill to advance MS issues. Advocacy staff and government relations volunteers work across the country, and with local policy makers in each state through our 50-state chapter network.

Discussion Question:
What motivates you to be an MS activist?
III – Making a difference – 10 simple ways to be an MS activist

Review the following tips and ideas with your Self-Help Group members. Ask them to pay close attention because in the next section, your group will make a decision about how to ACT on one of these ideas!

1. Join the MS Activist Network
   When the National MS Society needs to mobilize supporters to address issues that impact people living with MS, we call on our MS Activist Network. As a member of the Activist Network, you will receive “Action Alerts” via email. These alerts will keep you updated on important political issues and prompt you to take action at the local, state or federal levels to improve the quality of life for people living with MS. Circulate the Activist Network Sign Up sheet (included in this guide). Encourage your members to not only receive the emails but respond to them as well.

2. Meet with a legislator
   Visiting their district office, inviting them to one of your meetings, or even planning a trip to visit their office during the legislative session can be very effective. Our legislators work for us and they want to hear from us. WE are the credible experts on how MS can affect an individual, a family, a friend and a community.

3. Call a legislator
   Typically, we call legislators when there is a specific piece of legislation that is being considered and we want them to either support or oppose a bill. People are often skeptical of whether or not calling makes any impact…it does! Legislators keep a tally of how many people call about a particular issue. If a legislator receives 5-7 notifications about an issue it may move up on his or her priority list.

4. Write to a legislator
   State and local legislators appreciate receiving hand written notes from their constituents. An email can also be very effective and is often preferred by federal legislators.
5. Talk to family, friends and communities
Talk with people about the issues; why they’re important to you and how they can help make a difference. Hold a community forum or town hall and invite a guest speaker to talk about a particular topic.

6. Write a letter to the editor
Write a letter to your local paper about MS; what it’s like to live with MS in your community and how others can make a difference to improve the quality of life for people with MS.

7. Volunteer at events – recruit Activist Network members
Volunteer at Walk or Bike events or other local programs – encourage others to sign up for Action Alerts.

8. Follow state and local politics
Assign one of your group members to be an advocacy liaison or a “district activist.” Read about what’s going on in your community, watch the news, listen to the radio and communicate with National MS Society staff about ways we can either be involved or take a stand as an organization.

9. Share your story
Participate in our policy surveys and talk to staff about your interests and how MS affects your life. You can also share your story in our online story bank at http://www.nationalmssociety.org/MyStory

10. Address local issues
As a group, identify an issue that is in your community. Create an action plan to address that issue and ask National MS Society staff to support your efforts.

An example of local activism at work: An MS activist in Harrisonburg, Virginia worked on making her local library more accessible by asking local officials and library staff to create a drive-up window for returning books. The problem: Due to a significant number of stairs, people in wheelchairs or scooters could not enter the library from the front of the building and had to ask a staff member to open the back door of the library. It was inconvenient and unacceptable and she did something to change it.
Important: Remind people that as they work on becoming an MS activist, it’s important to be in touch with National MS Society staff partners so that we have a record of our advocacy efforts and the legislators that we are communicating with as an organization.

Discussion Question:
In what other ways can you be an MS activist?
IV – Take action!

Now it’s time to decide as a group if you will take action as MS activists. Will you write a letter-to-the-editor? Invite a legislator to your next meeting? Use the tips in the next section to make sure your efforts are successful.

Here are some questions you can ask your group members to get them thinking about how they want to take action:

Has our discussion inspired you to be an MS activist?

Which of the “10 ways to be an MS activist” sounds the most exciting?

Which sounds the most difficult?

Which ones would your group be able to act on quickly? / in the short-term (List them here).

Which ones would be long-term goals for your group? (List them here).

Ask your group members to vote on one (or more) action items that you will accomplish as a group.

How will you accomplish it?

- Name a point-person
- Set a timeframe
- Decide what your end result will be – what do you want to accomplish?
- What tools and resources will you need to be successful?
V – Tips for successful activism

Tips for writing letters or emails:

Write your letters on personal stationery and include your home address. If you use email, include your personal contact information.

- Tell the legislator that you live in his or her legislative district.
- Identify the subject you are writing about and the bill number, if known.
- Describe briefly the issue involved and (if applicable) what the bill would do.
- Illustrate the negative/positive impact the proposal would have on you and your community by sharing your brief story.
- Ask him or her directly to support (or oppose) the legislative proposal or bill that relates to the issue.
- Ask him or her to write back and explain where he or she stands on this important issue. You can also indicate that you will be following up.
- Include your return address in your letter and thank the legislator for paying attention to your concerns.

Sample Letter to Your State Legislator:

The Honorable John Doe
State Senate or House of Delegates
City, State, Zip

Date

Dear Senator (or Delegate) Doe:

My name is _______ and I live in your district. I have multiple sclerosis and I am writing to ask you to support legislation that would create a state Housing Trust Fund. A Housing Trust Fund would provide grants and loans to developers in order to increase the affordable housing stock in our state. MS is a very expensive disease and appropriate, affordable housing is critical for my family. I would like to know where you stand on this issue and will follow-up with you soon. Thank you for your time and dedication to our state.

Sincerely,

Your Name

Address
**Tips for calling your legislator:**

- Identify yourself. Clearly state your name, address and why you are calling. Indicate whether you are a constituent or not. Then express your concern about a specific issue.
- Keep it brief, concise, and courteous. Legislators and their staff are very busy. Limit your call to three or four minutes. Use written notes so you do not become confused or digress from the topic.
- Keep it focused. Assert your position and offer arguments that support it, but don’t be confrontational.
- Ask for a response. You can also demonstrate your concern by asking for a written reply. Provide your mailing address.

Sample Phone Script:

“Hello, my name is ____________, and I am a constituent of Senator/Delegate ________. I have multiple sclerosis and I am an active member of the _________ Self-Help Group.

Are you familiar with MS? MS is an unpredictable, often disabling disease of the central nervous system. I am calling today to express support for (opposition to)...”

Thank you for your time.”

**Tips for meeting with a legislator at his or her office:**

Be Prompt
Remember that legislators are extremely busy, especially during their legislative sessions. Make an appointment with his or her scheduler and be on time. If he or she is late, be patient. Do not be discouraged if you meet with a staff member in place of the legislator. Staff members keep legislators informed about the issues, and legislators frequently ask staff for advice on specific issues.

Be Prepared
Before you meet with your Senator or Delegate/Assembly Member know what you want to achieve. If you are asking for his or her support on a bill currently before the legislature, be sure you know the bill number, the approximate date it may be put to a vote, facts about how it will affect people living with MS and facts about how it may affect constituents in your legislator’s district.
Be Polite
Never threaten to oppose the legislator if he or she does not agree with your position. After listening to his or her point of view, politely suggest that he or she consider alternative perspectives and offer to provide additional information.

Be Influential
The National MS Society is a bipartisan organization. Therefore, you do not have to identify your political party. But you should demonstrate that the issue you are advocating about directly affects the legislator’s constituents. You can demonstrate this by sharing your own personal story.

Be Thorough
Write down the questions you want to have answered and bring them to the meeting. Once you are there, take notes. Be sure to write down the names of the staff members you meet. Having a record will be helpful. Also, if you do not know the answer to one of their questions it is okay to say so. Write the question down and ask a National MS Society staff member later.

Follow-Up
Follow-up with a thank you letter briefly outlining the different points covered during the meeting and attach any additional information and material. A thank you note serves two purposes - It maintains your relationship and reinforces your message. Also, be sure to share the results of your meeting with National MS Society staff!

Tips for writing a Letter to the Editor:

- Editors typically prefer to publish timely, concise letters that are about issues of local importance and interest.
- Before writing your letter, review the publication’s policy on letters to the editor. You should also read a few published letters to know the type of letters they publish and the expected format.
- Make sure you follow the publication’s directions for submitting letters to the editor. Typically, you have to submit them via email. You can usually find the directions on the publication’s website. Be sure to include your name and contact information as anonymous letters are rarely published.
- Keep your letter as short as possible by focusing on one or two major points. Support your position with facts and a compelling argument or story. Aim for no more than 250 words, and be sure to stay under any stated word limits.
• Ask someone, such as a National MS Society staff member, to review your letter before you submit it.

A sample Letter to the Editor:

World MS Day – May 30, 2012

Editor, Times-Dispatch:

World MS Day is the only global campaign to bring attention and awareness to multiple sclerosis (MS). On May 30th events will be held throughout the world to highlight this year’s theme – Living with MS. Our goal is to bring attention to the disease by sharing the stories of those who are affected.

There are 11,000+ faces of MS in Virginia. Dawn had to stop taking her MS medication because she could no longer afford it; Marlon had to move to a home that was near accessible transportation; Susan had to give up her dream job; Donna cares for her husband 24 hours a day without respite. These are our friends; our family; our neighbors; our fellow Virginians.

We know that MS destroys connections. It disconnects the mind from the body and people from each other. But what if we could defy this disease with the very thing it seeks to destroy: Connections. Would we share more knowledge? More questions? More answers? More hope? Maybe, by connecting enough small victories, we could win some really big ones.

Help the National MS Society forge imperative connections by participating in an event hosted by your local chapter, donating money for research or sponsoring a program. You can also join our network of MS Activists and advocate for policies that improve the quality of life for people living with MS in the Commonwealth. Chances are someone you know is affected by this disease. By coming together as a community on May 30th and throughout the year – we can and we will make a difference.

Learn more about World MS Day and share your story by visiting www.worldmsday.org. Connect at www.MSconnection.org

Ashley Chapman is the State Advocacy Manager for the four Virginia Chapters of the National MS Society. Follow her on Twitter @vaMScan.
V. Conclusion

Conclude the meeting with a thank you and a recap of what you’ve discussed and what you’ve decided as a group.

Provide your Self-Help Group members with the contact information of the National MS Society staff member that oversees advocacy in your area.

Provide them with any additional handouts you may have.

Additional resources:


Twitter Page: [www.twitter.com/MSActivist](http://www.twitter.com/MSActivist)


THANK YOU!

Thank you for taking the time to complete this guide and discuss advocacy with your Self-Help Group! As an MS activist you play a tremendous role in moving our advocacy efforts forward. Please be in touch with your National MS Society staff member and let them know how your group is taking action. Together, we will end MS forever.
MS Activist Network Sign-up Sheet

Return these completed sheets to your staff partner.

Name: ______________________________________________________

Street:______________________________________________________

City, State, and Zip: ____________________________________________

E-mail Address: _______________________________________________

___ I want to receive emails about MS issues and ways to get involved

___ I want to share my story or policy issue with the staff of the National MS Society

___ I want to visit with government officials about issues affecting people with MS

Name: ______________________________________________________

Street:______________________________________________________

City, State, and Zip: ____________________________________________

E-mail Address: _______________________________________________

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