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Become an
MS *Activist*



ACTIVISM 101

Mission

MS stops people from moving. The National MS Society exists to make sure it doesn't. We are a movement by and for people with multiple sclerosis, and we are moving together toward a world free of MS.

We aim to achieve our mission by:

- Funding cutting-edge research
- Driving change through advocacy
- Facilitating professional education
- Providing programs and services to help people with MS and their families move forward with their lives

Why be an advocate?

1. MS not only affects the person who has been diagnosed, but it also impacts their friends and family.
2. MS often strikes during the prime years of life. It not only affects personal relationships, but it can also dramatically change earning power.
3. MS costs about \$57,000 a year per person and \$20 billion for the country annually.
4. Over the course of disease progression, one-quarter of people living with MS will need long-term care; more than half will need help with one or more activities of daily living; and others will rely on government programs for access

to health care, disability benefits and long-term care.

5. As the leader in MS research funding, some of the significant research avenues funded by the Society include: immunology, nerve tissue repair, myelin biology, clinical trials, rehabilitation, psychosocial issues and health-care delivery.

MS advocacy involves putting a priority on MS research and enhancing care and quality of life for people with the disease until its cause and cure are discovered.

6. At the federal level, MS activists work toward health-care reform policies and we have secured nearly \$10 million over the past two years via the Congressionally Directed Medical Research Program for MS-related research
7. Our legislative priorities include increasing public funding for MS-related research; access to adequate, reasonably priced health insurance; and quality access to long-term care. We also advocate for the rights of all people with disabilities.

The Dos and Don'ts of Advocacy

Communication

When communicating, make sure to always keep two goals in mind. First, you want to affect your legislators' decisions on specific pieces of legislation. Second, you want to build relationships with your legislators that will lead them to respect and value your future communications on important issues.

Some Essentials to Advocacy

- 1.** When communicating with legislators or local leaders, be brief. These people lead busy lives, and you want to make the best use of the moments you have with them.
- 2.** Be persuasive; use facts and statistics to illustrate your points.
- 3.** Focus on the issues at hand.
- 4.** Do not be threatening or confrontational; this will not only cost you respect from legislators and local leaders, but also will diminish your legislative agenda and possibly destroy future interactions with such leaders.
- 5.** Do not be overly technical; speak in a way that is easy to understand without using technical words or phrases.
- 6.** Always include contact information such as your name, phone number and address in the event that follow up is needed.

COMMUNICATING WITH YOUR LEGISLATORS



Many people think you have to be a lobbyist or really know politics in order to speak with a legislator. The truth is that anyone can get in contact with their legislator to talk about public policy concerns. This chapter will give you tips and strategies for all aspects of communication with an elected official. These same ideas apply to local township officials, state department representatives and other representatives of government or public policy. Here are a few general rules to get you started:

> How to contact your legislator

Refer To reach a member of the senate, go to www.senate.gov and search by state.

To find your district representative, go to www.house.gov and search by zip code.

> How to set up a meeting with your legislators

- Call your legislators' offices several weeks in advance to set up a brief appointment (e.g. 15 minutes).
- Ask for the legislator's staff member who handles his/her schedule.
- Be sure to write down the date, time and person you spoke with for your records.
- Confirm the appointment in writing with a brief letter that includes the purpose, who will attend and the date.
- Call to reconfirm with the staff the day before.

- Provide staff with a list of participants (if there are others with you).
- If you are with a group, set up a prep meeting to discuss agenda, assign a facilitator and be sure that everyone has an opportunity to speak.
- Prepare a one-page fact sheet as a “leave behind” info sheet for the legislator and staff.
- Arrive early.
- Be courteous, respectful and brief.
- Be sure to ask the legislator questions and listen to their concerns.
- Thank the legislator.
- Follow up with a thank you including your key points.

➤ **Don't be afraid**

Legislators and their staff meet with regular citizens every day. Legislators want and need to hear from you, no matter their position or political affiliation. Remember, you're an expert on your own story and how the issues impact you.

➤ **Get to know your legislators**

Meeting one-on-one with your public officials is your right as a citizen. But this is just a first step. You can build an ongoing relationship with your public officials and keep them updated on MS issues.

➤ **Be prepared**

Be prepared so you can confidently update legislators and their staff on MS issues and boldly ask for their support. If talking points aren't provided on the issues, draft

your own. And take time to practice relaying your messages.

➤ **Understand the issues and your legislator's position**

Stay informed on MS issues and your legislators' positions on those issues. Check their voting record and committee assignments. Understand the opposing position on each issue.

➤ **You don't have to know all the answers**

No one expects you to have all the answers. It's most important to know how the issues impact you personally. If you're asked something you don't know the answer to, use it as an opportunity to follow up later.

➤ **Be open**

Be prepared to listen and speak. Be sure to structure the meeting so that you can do both.

➤ **Give examples**

Most members of the legislature are not in the medical field by profession, so the more examples you can give of the impact of your legislation on people with MS and their families in your own county, the more persuasive your arguments will be.

➤ **Share your personal story**

Share your personal story – it is the most compelling reason you have for the need to support MS issues. Start your conversation with a public official by sharing your personal experiences with multiple sclerosis and how the issue has impacted you, then ask for the support or change you need.

> **Role play**

Be sure to practice what you want to say to your legislator. This way, you will be more comfortable and you may be able to anticipate possible questions and prepare your responses.

> **Have fun**

Advocacy is a lot of fun. It is very rewarding to witness the outcome of something you have been working hard to achieve. There is a sense of achievement and success in knowing that you played a critical role in this advocacy accomplishment. So enjoy yourself. You are moving us closer to a world free of MS.

> **Follow up**

Be sure to follow up. Send a thank-you note. Maintain a conversation and continue to keep legislators and their staff updated on the issues. Do this throughout the year. Schedule a follow up visit or invite them to a chapter event. This is important for establishing an ongoing relationship.

> **Be flexible**

You may not get to meet with the

legislator. Do not be offended by this. It may be because they have been called in to vote or have a committee hearing or other obligation. You may meet with an aide instead. Aides can be very important in helping carry your message forward. The same rules of effective communication apply to aides. Send the aides thank you notes as well.

An important note: When you work with us as an MS activist, you represent the Society. This means that the opinions you express while speaking on our behalf or at our events are seen as reflective of the opinions of the Society. You may have differing opinions regarding some of our stances as a result of political or religious views. Please remember that while acting as a spokesperson for the Society, you should represent our positions. If, while at an event, a person with whom you are speaking wishes to debate a stance the Society has taken on a certain issue, just let them know that our positions are determined without reference to political parties. Instead, positions are taken according to what has been shown to be the most productive and positive for people living with MS and the Society's vision of moving together toward a world free of multiple sclerosis.

A disability is a normal part of life and most people who live long enough will experience a disability in their lifetime.

The difference between a disability and a handicap is that people with disabilities can function in everyday life. We cannot get rid of disabilities, but we can work at keeping them from becoming handicaps.

Stereotypes to avoid

- People living with disabilities are “courageous.”
- People’s lives are ruined by a disease or a disability.
- A disability dominates a person’s life.
- A disease or a disability is caused by something that someone or something that the person did or did not do.

GENERAL LANGUAGE*

PHRASES TO AVOID	Use instead
Wheelchair-bound, confined to a wheelchair	Uses a wheelchair
Suffer, afflicted, victim, handicap, invalid, crippled, stricken	Person with a disability
Handicapped/ disabled parking	Accessible parking
Normal person, healthy person	Person without a disability, able-bodied person

Note: Always focus on and emphasize on the positive

MS-SPECIFIC LANGUAGE

PHRASES TO AVOID	Use instead
MS person/patient/client	Person living with MS/person who has MS
MSers	Person with MS
People suffering from or afflicted with MS	Person living with or affected by MS
When she was stricken with MS	When she was diagnosed with MS

It cannot be emphasized enough that the person always comes first and the disability comes after. This way you identify the person, rather than the disability.

Language for those who care

What do you call a family member, significant other or caregiver?

Never use the word caretakers when referring to those who care for people with MS because caretakers are for cemeteries and properties – NEVER people.

People who are paid to provide care are referred to as “personal assistants.”

“Care partnerships” involve a give and take relationship between caregivers and people requiring care.

Words into Action

Words are an important tool in public policy. They can highlight an important issue, bring attention to an issue you are advocating for, make action happen, communicate crucial analysis of an important piece of legislation or share stories of how a particular issue affects you, the constituent.

When communicating in writing to an elected official or other government representative, please refer to the following guidelines:

- Be formal. Try to type your letter on a computer or typewriter.
- Be specific with what you want. If you have bill numbers, make sure to reference them in the letter.
- Be concise. Legislators are busy, so stick to the facts.
- Share your story or that of someone else you know to make the issue as compelling as possible.
- Thank them for their time and advocacy on your behalf.
- Include your name, address and phone number in the letter.

Sample letters are included at the end of this chapter for your assistance.

When communicating by phone, please refer to the following guidelines:

- Identify yourself to the person who answers the phone. Be sure to say that you are a resident and a constituent in the legislator's district.
- Tell the legislator the issue or bill number

you're calling about. Give your position and reason for your position.

- Briefly explain the likely impact of a bill on your county and on the legislator's constituents.
- Be polite.
- Keep party politics out of the discussion.
- Thank your legislator for his or her consideration of your views.
- If the legislator is unavailable, give a staff member your message.

When communicating by e-mail, the letter-writing guidelines apply. A few additional guidelines include:

- Avoid informal language. E-mail to a legislator should be treated as seriously as a traditional letter. Resist the temptation to use the informal language and symbols often associated with e-mail communications. Never use impolite language or make demands.
- Be sure your e-mail address is of a professional nature
- Include your full address and zip code. Make sure the text of your e-mail includes your full name and street address, including zip code. Many legislative offices at the federal level screen e-mails for address information identifying the sender as a constituent. E-mails that may appear to come from outside the district are unlikely to be read and might be blocked by filtering programs.



Guide for writing business letters

Business letters should always include:

- The date
- Recipient name and address
- Salutation (usually "Dear Mr." or "Ms." unless you are on familiar terms; see below for appropriate salutations in e-mails and when writing to government officials)
- Closing ("Thank you," "Sincerely or "Warmest regards" – only capitalize the first letter of the closing)
- Note any enclosures or courtesy copies at the bottom

Addressing a government official

➤ **US President:**

President (full name)
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Dear Mr./Ms./Mrs. President:

➤ **US Senator:**

The Honorable (full name)
US Senator
Washington DC address OR Pennsylvania/
New Jersey address (look up on the web
through each Senator's page)

(Use DC address when Congress is in session; otherwise use local address)

Dear Senator (last name):

WRITING TO YOUR LEGISLATORS 101

“
Letters are the most significant memorials a person can leave behind them.”

~JOHANN WOLFGANG VON GOETHE

Purpose:

Advocates write to legislators to inform them of the issues that are affecting their lives and the lives of others, to urge them to find a resolution for those issues and to leave a lasting impression on them.

Keys to writing the letter:

- Be memorable
- Give compliments and thanks whenever possible
- Be short and sweet; limit yourself to a page
- State clearly what it is you want
- Urge the legislator to write back to you with his or her resolution to your issue
- Remain neutral, as the legislator you write to may not be of your particular party

> **US Representative:**

The Honorable (full name)
US Representative
Washington DC address OR Pennsylvania/
New Jersey address (look up on the web
through each Senator's page)

(Use DC address when Congress is in
session; otherwise use local address)

Dear Congressman/Congresswoman (last
name):

> **Governor:**

The Honorable (full name)
225 Main Capitol Building
Harrisburg, Pennsylvania 17120

Dear Governor (last name):

> **State Senator:**

The Honorable (full name)
State Senator (if to President, use
President of the Senate)
Interim address OR State Capitol address

(Use State Capitol address when Legislature
is in session; otherwise use interim address)

Dear Senator (last name):

> **State Representative:**

The Honorable (full name)
State Representative (if to Speaker, use
Speaker of the House)
Interim address OR State Capitol address

(Use State Capitol address when Legislature
is in session; otherwise use interim address)

Dear Representative (last name):

First paragraph:

Introduce yourself and/or your organization

Give brief background about yourself,
including whether you or someone you
know has MS

Introduce the reason you are writing

Body of the letter:

State the issue or the concern

Provide a story illustrating the issue and
describe how it has impacted you or
someone you know

State what can happen if the issue goes
unresolved

Propose a possible solution to the problem

Third paragraph:

Briefly address one or two issues they have
solved in the past. Thank them and explain
how the resolved issues have improved your
and/or someone else's way of life.

NOTE: If there is nothing to compliment
the politician on, move on to the
conclusion. Don't make things up or risk
seeming insincere.

Conclusion:

Thank the legislator for reading your letter

Thank them again for past assistance and
tell them that you hope they will address the
current issue or concern

Request that they write back with an answer
to your problem

➤ **Secretary of Education:**

The Honorable (full name)
Secretary of Education
Pennsylvania Department of Education
333 Market Street
Harrisburg, PA 17126

Dear Secretary (last name):

➤ **State Treasurer:**

The Honorable (full name)
State Treasurer
900 Court Se. NE, Rm 159
Salem OR 97301-4043

Dear Treasurer (last name):

➤ **Commissioner of Labor and Industries:**

The Honorable (full name)
Secretary of Labor and Industries
Room 1700
7th and Forster Streets
Harrisburg, PA 17120

Dear Secretary (last name):

➤ **Attorney General:**

The Honorable (full name)
16th Floor
Strawberry Square
Harrisburg, PA 17120

Attorney General (last name):

What NOT to do

- Be rude
- Curse, threaten or blame
- Use slang terminology
- Write more than one page
- Address the legislator by his or her first name at the beginning of the letter
- Mail a letter if it is dirty, bent or marked-up
- Use fancy or illegible fonts

What to do:

- Be polite and professional
- Address the legislator as they are known in the professional world (e.g. Dr. Brown)
- Write a one-page letter
- Use a simple font
- Thank the legislator for their previous efforts to make life easier for you or for your loved ones
- Makes sure that the final copy of the letter is neat and free of stains, spots or folds
- Use spell check

Sample letters are included at the end of this chapter for your assistance.

➤ **Secretary of State:**

The Honorable (full name)
Secretary of State
North Office Building
Harrisburg, PA 17120

Dear Secretary (last name):

➤ **County Commissioner:**

The Honorable (full name)
County Commissioner
Address
City, State Zip

Dear Mr./Mrs./Ms. (last name):

➤ **Mayor:**

The Honorable (full name)
Mayor of (place name)
Address
City, State Zip

Dear Mayor (last name):

➤ **City Council Member:**

Council Member (full name)
(place name) City Council
Address
City, State Zip

Dear Council Member (last name):

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- Tell the legislator the issue or bill number you're calling about. Give your position and the reason for your position.
- Briefly explain the likely impact of a bill on your county and on the legislator's constituents.
- Be polite.
- Keep party politics out of the discussion.
- Thank your legislator for his or her consideration of your views.
- If the legislator is unavailable, give a staff member your message.

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- Avoid informal language. E-mail to a legislator should be treated as seriously as a traditional letter. Resist the temptation to use the informal language and symbols often associated with e-mail communications. Never use impolite language or make demands.
- Be sure your e-mail address is professional and not offensive.
- Make sure the text of your e-mail includes your full name and street address, including zip code. Many legislative offices

at the federal level screen e-mails for address information identifying the sender as a constituent. E-mails that may appear to come from outside the district are unlikely to be read and might be blocked by filtering programs.

When visiting your legislators

- When visiting your legislators, make sure you are prompt, prepared, polite and thorough, and be sure to follow up.
- You can offer public testimony by calling the committee holding a hearing and asking to be placed on the “witness list.” Once you have done this, follow up with a letter confirming your request on paper.
- When providing testimony, make sure that you identify yourself and where you reside.

State your position as clearly as possible and be sure to mention that you have first-hand experience, because it establishes credibility in what you have to say.

- Like all other times you communicate with legislators, remember to be courteous and not confrontational.
- Make sure you dress in a professional manner, as this will reflect that you take your position and the hearing seriously.
- Make sure you are brief. Send copies of your statement to your legislator urging his or her support or opposition for the topic.
- Bring copies of your testimony to submit to the committee and share copies with the media.

CONTACTING THE MEDIA

Using the media is an important tactic in activism. It can generate attention to an issue, help garner public support for an issue or publicize success stories. This chapter will focus on the different ways to use media for your grassroots efforts. It also includes a list of frequently asked questions on multiple sclerosis as well as position statements on controversial issues such as medical marijuana and stem cell research.

Using the media

The media includes television, radio and print. It can include coverage of an event, an interview with an individual affected by a particular issue or getting a letter to the editor published in your local paper.



Find and define the story

What is the story? Make sure you have all the facts and information ready before reaching out to the media. Make sure that whoever is going to be interviewed has agreed to share their story. Remind them that if they have multiple sclerosis and have not told others of their diagnosis, media attention will let friends, family and co-workers know. People often do not think about the aftermath of a story or its potential reach.

Contacting reporters

Traditionally, getting attention for your public policy issue simply required sending out a press release to local news outlets. While that approach can still be useful, the personal touch – whether it's via e-mail, phone or by mail – can make all the difference. Find out which reporters have covered similar stories in the past and contact them directly. Tell them why the issue is important and how it is affecting you and other local people affected by MS.

Preparing for an interview

Getting ready for an interview with a reporter can be an intimidating experience. The most important element of every interaction with a journalist is to remember that you can control the outcome by following these basic principles:

- Be prepared to say and repeat your two or three key messages about the issue as often as possible. Have them written down and rehearsed.
- Bridge from one subject to another in order to communicate your key messages effectively. First answer the direct question, then transition to your message using phrases such as:
 - What's important to remember, however...
 - What that means is...
 - That's a good point, but I think it's important to remember...
 - Let me put that in perspective...
 - Use personal stories to provide examples. Facts are great, but what people really remember and want to hear about are the stories of people affected by MS.
 - Always leave people with a call to action. A website. A phone number. Something that allows the public to get involved.
 - Slow down. Most people speed up during interviews; it works better if you slow down and give yourself time to think through what you are saying.
 - Be brief. Keep answers – especially for TV or radio – no longer than 25 seconds.

Consider a letter to the editor

A letter to the editor is like a letter to your community on an issue of importance. Here are a few guidelines:

- Include your name, address and phone number, and address your letter to Letters to the Editor
- Like other communications, make your letter concise and stick to the facts
- Check your local newspaper for additional rules or guidelines before you submit
- When published, make copies and make sure to let chapter know so that we can save it for our files as well. Examples of letters to the editor are at the end of this chapter

Frequently Asked Questions

You may need to provide a brief overview of some aspect of multiple sclerosis. These answers can serve as a guide as to what you can use for some of the more frequent questions posed. If you are being interviewed about your own experience, make sure to personalize your experience, as it makes for a more compelling story.

What is multiple sclerosis?

Multiple sclerosis is a chronic, unpredictable disease of the central nervous system (the brain, optic nerves, and spinal cord). It is an autoimmune disorder in which the immune system incorrectly attacks the person's healthy tissue. MS can cause blurred vision, loss of balance, poor coordination, slurred speech, tremors, numbness, extreme fatigue, problems with memory and concentration, paralysis, blindness and more. These

problems may be permanent or may come and go. Most people are diagnosed between the ages of 20 and 50, although individuals as young as 2 and as old as 75 have developed it. MS is not considered a fatal disease as the vast majority of people with it live a normal lifespan. But they may struggle to live as productively as they desire, often facing increasing limitations.

Who gets MS?

Anyone may develop MS, but there are some patterns. Nearly four times as many women as men have MS. Studies suggest that genetic factors make certain individuals more susceptible than others, but there is no evidence that MS is directly inherited. It occurs more commonly among people with northern European ancestry. People of African, Asian and Hispanic backgrounds are also diagnosed with MS. However, the incidence is much lower.

How many people have MS?

Approximately 400,000 Americans have MS, and every week about 200 people are diagnosed. Worldwide, MS affects about 2.5 million people. Because the Centers for Disease Control and Prevention (CDC) do not require U.S. physicians to report new cases, and because symptoms can be completely invisible, the numbers can only be estimated. In N.J., 13,000 people are diagnosed with MS, and in Pa. 19,000.

What are the typical symptoms of MS?

Symptoms of MS are unpredictable, varying from person to person and from time to time in the same person. For example: One person may experience abnormal fatigue and episodes of numbness and tingling. Another could have loss of balance and muscle

coordination making walking difficult. Still another could have slurred speech, tremors, stiffness and bladder problems.

Sometimes major symptoms disappear completely and the person regains lost functions. In severe MS, people have symptoms on a permanent basis, including partial or complete paralysis and difficulties with vision, cognition, speech and elimination.

What causes the symptoms?

MS symptoms result when an immune-system attack affects myelin, the protective insulation surrounding nerve fibers of the central nervous system (the brain and spinal cord). Myelin is destroyed and replaced by scars of hardened "sclerotic" tissue. Some underlying nerve fibers are permanently severed. The damage appears in multiple places within the central nervous system.

Myelin is often compared to insulating material around an electrical wire; loss of myelin interferes with the transmission of nerve signals.

Is MS fatal?

In rare cases, MS is so malignantly progressive it is terminal, but most people with MS have a normal or near-normal life expectancy. Severe MS can shorten life.

Does MS always cause paralysis?

No. Moreover, the majority of people with MS do not become severely disabled. Two-thirds of people who have MS remain able to walk, though many will need an aid, such as a cane or crutches, and some will use a scooter or wheelchair because of fatigue, weakness, balance problems or to assist with conserving energy.

Is MS contagious or inherited?

No. MS is not contagious and is not directly inherited. Studies do indicate that genetic factors may make certain individuals susceptible to the disease.

Can MS be cured?

Not yet. There are now FDA-approved medications that have been shown to “modify” or slow down the underlying course of MS. In addition, many therapeutic and technological advances are helping people manage symptoms. Advances in treating and understanding MS are made every year, and progress in research to find a cure is very encouraging.

What medications and treatments are available?

The National Multiple Sclerosis Society recommends that a person consider treatment with one of the FDA-approved “disease-modifying” drugs as soon as possible following a definite diagnosis of MS

with active or relapsing disease. These drugs help to lessen the frequency and severity of MS attacks, reduce the accumulation of lesions (areas of damage) in the brain, and may slow the progression of disability.

In addition to drugs that address the basic disease, there are many therapies for MS symptoms such as spasticity, pain, bladder problems, fatigue, sexual dysfunction, weakness and cognitive problems. People should consult a knowledgeable physician to develop a comprehensive approach to managing their MS.

Why is MS so difficult to diagnose?

In early MS, symptoms come and go that might indicate any number of possible disorders. Some people have symptoms that are very difficult for physicians to interpret, and these people must “wait and see.” While no single laboratory test is yet available to prove or rule out MS, magnetic resonance imaging (MRI) is a great help in reaching a definitive diagnosis.

Position Statements

There are some issues that are controversial. Below are the official policy statements of the National Multiple Sclerosis Society on medical marijuana, stem cell research and animal research. When representing the Society, it is important that you use the official policy statements.

Stem Cell Research

To find new ways to prevent, slow the progression or repair the effects of multiple sclerosis, the National Multiple Sclerosis Society supports the conduct of scientifically meritorious medical research, including research using human cells, in accordance with federal, state and local laws and with adherence to the strictest ethical and procedural guidelines. The Society believes that all promising avenues that could lead to the cure or prevention of MS or relieve its symptoms by repairing MS damage must be explored—including expanding the stem cell lines that are available for federally funded research.

Animal Research

The National MS Society is dedicated to finding a cure for MS by stimulating and supporting clinical trials, including those using animals. Organizations committed to finding a cure for diseases like MS are left with little choice: the U.S. Food and Drug Administration regulations prohibit testing drugs on humans until they have been shown to be safe in animals.

Cannabis/ Medical Marijuana

Conflicting results of previous research, coupled with the need for additional therapies to treat symptoms of MS, make

it important that more research be done on the potential of marijuana and its derivatives. The National MS Society is funding a well controlled study on the effectiveness of different forms of marijuana to treat spasticity in MS and established a task force to examine the use of cannabis in MS. This task force had made specific recommendations on the research that still needs to be done to answer pressing questions about the potential effectiveness and safety of cannabis in treating MS.

CCSVI

Preliminary studies have suggested that a phenomenon called chronic cerebrospinal venous insufficiency (CCSVI), a reported abnormality in blood drainage from the brain and spinal cord, may contribute to nervous system damage in MS. The Society shares in the public urgency to advance the understanding of CCSVI as quickly as possible. The U.S. Society and the MS Society of Canada are devoting \$2.4 million to the funding of seven initial grants that focus on the role of CCSVI in the MS disease process. The new studies will carry out significant steps needed to confirm the phenomenon originally described by Dr. Paolo Zamboni and resolve the questions raised by him and others as to whether CCSVI is a cause of MS or related to MS in some other manner. Medical institutions and health care providers require research data confirming the validity, necessity and safety of any procedure they provide, and in their view, that data is not yet available as it relates to the relationship between CCSVI and MS. Adding clarity to the relationship between CCSVI and MS is essential in assisting people with MS secure any treatment they may consider.

State Failing Adults, Not Dogs

To the Editor:

Recently, the state of Pennsylvania updated its laws to further extend protections for dogs. What about vulnerable adults who are subjected to abuse and neglect? Pennsylvania is one of only six states without protective services in place for adults ages 19-59. The sad fact is that dogs in Pennsylvania are better protected from abuse than adults.

The state is failing to protect a large number of adults who are physically and cognitively impaired due to multiple sclerosis (MS). These are adults who are forced to live in unsafe and unsanitary conditions, held captive by loved ones or their caregivers. They have no way of seeking help. Relocating them to a safe environment is not always possible because they often live with, and are dependent on, their abusers.

Adult protective service legislation is working in other states. In Oregon, a Portland couple was recently arrested for subjecting a couple in their care to three years of financial, psychological and physical abuse, including strangulation, assaults and dog bites. In Ohio, a woman was recently charged with abusing her 22-year-old daughter who is not able to walk or talk. In

Pennsylvania, we know people are suffering at the hands of family members and care providers. We just don't know how many.

Health-care workers often seek assistance from the National MS Society when they believe their patients' caregivers are taking advantage of them or not caring for them properly. Without a law protecting these vulnerable adults, there's not much we can do. It would be nice to be able to raid the homes of all those we know are being victimized; unfortunately, that's only a solution for puppy mills.

The only chance these individuals have is to create adult protective services. Two pieces of legislation stand ready to assist them: House Bill 361 and Senate Bill 1049. A message needs to be sent to legislators that protecting dogs is important and necessary, but protecting human life is more important. Tell your legislator to help make adult protective services legislation a reality.

Too many vulnerable adults have already suffered ~~while waiting for this law.~~ Don't make them wait anymore.

JOHN H. SCOTT
National Multiple
Sclerosis Society
Philadelphia

Needed: A better city for wheelchair users

I'd like to commend Daniel Rubin for two recent columns on Philadelphians' struggles to navigate their neighborhoods in wheelchairs ("Bumpy roads for wheelchairs," Jan. 31, and "City is a rough ride for wheelchair users," Jan. 28).

The columns raise important issues about access, and highlight the difficulties that people with disabilities have in getting around a city built in colonial times that has been rarely renovated with wheelchairs in mind.

There should not be two Philadelphias, one for the able-bodied and one for the disabled. We hope Mayor Nutter and his new administration will begin to address these inequalities. Until the city gets involved and starts demanding answers from restaurants, retailers, and its own employees who refuse to make accommodations for people with disabilities, no real change will occur.

John H. Scott

President

Greater Delaware Valley Chapter

National **MS** Society

Philadelphia

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WEB RESOURCES

Federal government resources

> **United States Senate**

Information about Senate members, committees, committee rosters and member information.

www.senate.gov

> **U.S. House of Representatives**

Information about House members, committees, committee rosters and House legislation.

www.house.gov

> **White House**

Includes recent news, press releases and statistics.

www.whitehouse.gov

> **Thomas**

Information about bills, House/Senate floor action committee reports, member e-mail and home pages, and links to other congressional websites.

<http://thomas.loc.gov>

National resources

> **National Multiple Sclerosis Society**

Government relations page provides information about federal advocacy issues, activism blog and policy information.

www.nationalmssociety.org

> **Families USA**

Nonprofit consumer organization that provides information on health care. Numerous publications and resources for consumers are available.

www.familiesusa.org

> **Henry J. Kaiser Family Foundation**

Nonprofit foundation that researches health-care policy issues. Information on health-care policy on the federal and state level.

www.kff.org