



Helping Others with Multiple Sclerosis

Information about being a volunteer, donor, or research participant

This handout details ways patients with multiple sclerosis can volunteer to help others, donate to further research, or participate in a research study.

Here are some of the ways that you can help others with multiple sclerosis (MS):

- Volunteer your time and experience.
- Participate in research.
- Donate to the Western Multiple Sclerosis Center at UWMC.

Volunteer Your Time and Experience

Your time and experience are some of the most valuable contributions that you can make to others with MS. There are many opportunities to volunteer with community organizations. You can contact them directly for volunteer activities. Many of these organizations are listed in the resource section of this manual.

University of Washington Medical Center also has volunteer opportunities. Contact 206-598-4218 for further information.

Your local chapter of the **National Multiple Sclerosis Society** uses volunteers. These include helping with office work, telephone contact with people with MS, support group participation and leadership, and fund raising. Training is available for many of these positions. Contact your local chapter for further information. The number for the Greater Washington Chapter is 206-284-4236, or 1-800-800-7047. (See section 14 of this manual for additional resources and their phone numbers.)

The **Multiple Sclerosis Association of King County** has volunteer opportunities. These include helping with office work, telephone assistance, support group participation and leadership, and fund raising. Training is available for many of these positions. Contact 206-633-2606 for information.

Participate in Research

Research studies on multiple sclerosis conducted at the University of Washington include:

- Studies into the cause of the disease.
- Study of factors that influence the disease.
- Treatment of symptoms.
- Treatment of the disease.
- Studies of rehabilitation techniques.
- Studies of the human impact of the disease including psychological and vocational issues.

You may learn about current studies being done at the Western Multiple Sclerosis Center by calling one of the two coordinated research centers. This does not obligate you to participate in a research study. Your name will be placed on a contact list if you wish to be informed about upcoming studies that you may be eligible for.

- **Multiple Sclerosis Research Center at UWMC** at 206-616-UWMS (8967) studies underlying causes of the disease, treatments of the disease and treatments of symptoms.
- **The Multiple Sclerosis Rehabilitation Research and Training Center** at 1-888-634-MSRT (6778) studies physiologic function, symptom management, rehabilitation techniques, and the human impact of the disease.

The primary purpose of participating in research is to advance our knowledge of the disease and its treatments. Participation in a research study may or may not directly benefit you. Some studies involve treatments that may directly benefit you. Many, but not all, studies have placebo treatments. Placebos look just like the study medication, but do not contain any active ingredients. Placebos are used as controls for studies. Even if you do not directly benefit from a study, the knowledge gained will advance the management of this disease.

Participate in Pathology Studies

Tissue from people with MS who have died is extremely important in advancing our understanding of this difficult disease. This is the only way that we can directly study the changes that occur in the brain with MS. Patients who have been seen at least once at University of Washington Medical Center are eligible for a free autopsy when they die. The cost of transporting the body to and from the University is not included. Notify the funeral director of the patient's wishes at the time of death. The funeral director should then contact the admissions office of University of Washington Medical Center at 206-598-4310 for further instructions. An

autopsy does not alter the appearance of the body or delay the funeral.

Donate to the Western Multiple Sclerosis Center
Charitable Donations

Charitable contributions to the Western Multiple Sclerosis Center are used to enhance patient care, expand upon MS research, and educate our staff. Because donors may have a special interest they wish to support, we offer them the opportunity to direct their contributions for specific uses. Ranging from support of an individual doctor's research to support of an entire program to support of the Multiple Sclerosis Center in general, donors decide where their money is spent. In this way, even a small contribution can make a big difference. Donations of any size are tax-deductible and may be matched by the donor's employer. We invite you to join the Western Multiple Sclerosis Center in changing the lives of people with multiple sclerosis. Your help will be greatly appreciated. If you are able to make a contribution, please contact:

Western Multiple Sclerosis Research Center at UWMC
at 206-616-UWMS (8967) to support research into the mechanism of disease, medications to modify the course of the disease, or neurology issues.

The Multiple Sclerosis Research and Training Center at 1-888-634-MSRT (6778) to support rehabilitation and research into rehabilitation techniques and the human impact of the disease.

Travel Donations

The donation of frequent flier miles allows nursing staff, research staff and doctors to attend scientific and educational meetings they otherwise would not be able to attend. The research centers can tell you if there is an upcoming meeting of interest to staff members. This type of transaction is a bit complicated however; so if there is interest in donating frequent flier miles to a Western Multiple Sclerosis Center staff member, please contact:

**Multiple Sclerosis Research Center at UWMC at
206-616-UWMS (8967)**

**The Multiple Sclerosis Research and Training Center at
1-888-634-MSRT (6778).**

Major Donations to the Western Multiple Sclerosis Center

Major donations may also be made to support the current activities or to establish new programs or services for either of the multiple sclerosis centers. Major gifts to establish endowments provide permanent funding for research, training, and clinical care and often provide significant tax advantages. In addition to cash, some creative ways to contribute include:

- Appreciated stocks/securities
- Real estate
- Fixed Income Plans (Charitable Gift Annuities)
- Variable Income Plans (Charitable Remainder Unitrust)
- Wills, bequests, etc.
- In-kind donations/other

Questions?

Call 206-598-3344

Your questions are important. Call your doctor or health care provider if you have questions or concerns. UWMC Clinic staff are available to help during regular business hours.

**Western Multiple
Sclerosis Center at
UWMC
206-598-3344**

If you would like more information about any of the options listed above (or any other options you may be considering), please contact UWMC Medical Affairs Development Office at Box 358220, Seattle, WA 98195-8220 or call 206-543-5686.

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