



ADVOCACY

August 20, 2010	CC: Programs and Services
<u>Self-Advocacy Tools Revised for Internet Search Capabilities</u>	

The Society's self advocacy tools, found under the home page left navigation tool, "Living with MS," are revised for Google search engine capabilities. Several additional, key search words will now provide relevant and current content results for Society website searches and internet users, while content largely remains the same, due to positive user feedback.

People living with MS and those that care about them will find resources here for effective self advocacy skills across life settings and specific resources related to:

- Family
- Employment
- Community
- Health Insurance
- Medical and Long-Term Care
- SSDI

You are encouraged to peruse this site to become familiar with its content and to direct clients to it for a self-taught curriculum. Questions regarding this site may be directed to Renee Vandlik at 414-312-7430 or Renee.Vandlik@nmss.org.



CHAPTER PRESIDENTS

August 20, 2010	CC:
	All Departments
<u>2010 Lifetime Achievement Award</u>	

The Lifetime Achievement Award is presented to volunteers with thirty-five (35) or more years of service who have steadfastly given of themselves in the movement to a world free of MS.

In 2010 we honor one individual for her commitment!

Marjorie Schulz gave 62 years of her life to the MS Movement. She created a resource in the Cincinnati community for people living with MS before multiple sclerosis was acknowledged, accepted and understood.

Even before joining the National MS Society, the chapter provided programs and services, while also building a community of local support. Marjorie organized efforts to raise funds to support the organization long before fundraising was a common practice. Supporters walked from house to house collecting donations and educating people about MS. In 1952, the Ohio Valley Chapter joined the National MS Society – and as Marjorie once described, “we never looked back.”

In her later years, Marjorie continued to volunteer in the chapter office. Always dedicated, she inspired the staff and reminded volunteers and fundraisers of the importance of their work.

Marjorie passed away in April and the Ohio Valley Chapter lost their most treasured piece of chapter history.

We honor Marjorie Schulz, Founder of the Ohio Valley Chapter, for her lifetime dedication to the MS movement.

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CHAPTER PRESIDENTS

August 20, 2010	CC:
	All Departments
<u>2010 Volunteer Hall of Fame</u>	

Congratulations to the following volunteers inducted into the Volunteer Hall of Fame for 2010!

Advocacy:

Jeffrey Gingold nominated by Colleen Kalt and Mary Hartwig of the Wisconsin Chapter
Fiona Hoey nominated by Ruth Brenner and PJ Weiner of the New York City/Southern New York Chapter

Jerry Hogenmiller nominated by Colleen McGuire and Jennifer Strayer of the Western Pennsylvania Chapter

Bill MacNally nominated by Holly Anderson and Emily Wilson of the Minnesota Chapter

Doris Matchett nominated by Chris Broullire and Diane Metzger of the National Capital Chapter

Elizabeth Page nominated by Jeff Furst and Abby Carter Emanuelson of the Eastern North Carolina Chapter

Funding the Mission:

Lynda Baris nominated by Phyllis Robsham and Paula Eichholz of the Gateway Area Chapter

Rosanne Esposito nominated by Patty Shepherd-Barnes and Erica de Klerk of the Greater Northwest Chapter

E. Michael Houlihan nominated by Phyllis Robsham and Paula Eichholz of the Gateway Area Chapter

Bill Klesse nominated by Tony Ralf of the South Central Region

Honorable Nicholas J. Maiale nominated by Tami Caesar and Anne Krishnan of the Greater Delaware Valley Chapter

Barry Roberts nominated by Jeff Furst and Shannon Hinson of the Eastern North Carolina Chapter

Jack and Susan Turben nominated by Janet Kramer and Guyla Wehman of the Ohio Buckeye Chapter

Health Professionals:

Dr. Gary Birnbaum nominated by Holly Anderson and Emily Wilson of the Minnesota Chapter

Rene Elkin nominated by Ruth Brenner and Robin Einbinder of the New York City/Southern New York Chapter

Thomas Leist, MD, PhD. Nominated by Tami Caesar and Karen Mariner of the Greater Delaware Valley Chapter

Deanna Markley, PT nominated by Kay Julian and Amy Goldstein of the Mid America Chapter

Marie A. Namey nominated by Janet Kramer and Guyla Wehman of the Ohio Buckeye Chapter

Programs and Services:

David Chaikin nominated by Holly Anderson and Emily Wilson of the Minnesota Chapter
Stephanie Fisher, MA nominated by Leon LeBuffe and Denise Nowack of the Southern California Chapter

Beth Rudisill nominated by Jeff Furst and Kaye Gooch of the Eastern North Carolina Chapter

Fred Schwartz nominated by Tami Caesar and Karen Mariner of the Greater Delaware Valley Chapter

Sylvia White nominated by Tami Caesar and Karen Mariner of the Greater Delaware Valley Chapter

Scientific Researchers:

Marie Filbin, Ph.D. nominated by Ruth Brenner and Robin Einbinder of the New York City/Southern New York Chapter

Dr. John Fleming nominated by Colleen Kalt and Kim Kinner of the Wisconsin Chapter

Mark D. Mannie, PhD. nominated by Jeff Furst and Kaye Gooch of the Eastern North Carolina Chapter

Thank you to the selection committees led by Volunteer Hall of Fame liaisons Renee Vandlik: Advocacy, Susan Goldsmith: Funding the Mission, Kristin Summers: Health Professionals, Kim Koch: Programs and Services and Dr. Patricia O’Looney: Scientific Researchers.

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CHAPTER PRESIDENTS

August 13, 2010	CC:
	All Departments
2010 Volunteer of the Year	

The National MS Society is proud to announce that Tom Holtackers has been selected to receive the Society's most prestigious award, Volunteer of the Year! Tom was nominated by Holly Anderson and Emily Wilson of the Minnesota Chapter.

Tom first volunteered for the National MS Society in 1979, a year before his own diagnosis and the realization that he would face a life with multiple sclerosis. Over time, he transitioned from victim, to survivor, to conqueror, embarking on a lifelong mission devoted to a world free of MS. His 37-year career as a physical therapist gives him a unique perspective on living, working and thriving with MS; and he is dedicated to sharing his knowledge and experience with others. Tom's involvement with the Society spans more than three decades. He is an active volunteer with the Minnesota Chapter — at programs and events and on countless boards and committees, including more than 20 years on the chapter's Board of Trustees.

Nationally, Tom has served on the Programs Advisory Council, including a term as Chair, and he was a member of the Assisted Living Task Force. He also led national self-help group leader training and presented at a variety of conferences. In 2008, Tom spearheaded one-of-a-kind fitness programs designed to mobilize and empower others with MS to live well — mentally and physically. The MS Fitness Team and Club launched in three locations, making exercise easy and accessible for hundreds of people throughout the area.

Tom is an active fundraiser and athlete, currently training for his ninth Challenge Walk, and his optimism, commitment and passion for our Movement have benefitted the people of Minnesota and throughout the country. He is a bold warrior against MS, inspiring others with his positive attitude and contagious energy.

Tom's courage is an inspiration. His positive attitude, ability to motivate others and passion for our mission are qualities we recognize as we name Tom Holtackers the 2010 Volunteer of the Year.

We are sincerely grateful for Tom's unwavering commitment to the Society and the movement toward a world free of MS.

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CHAPTER PRESIDENTS

Date: 8/20/10	CC:
<u>Certification Standards</u>	
Action Requested/Deadline:	

At the July 23rd meeting of the Chapter Relations Committee, National Board of Directors, a recommendation from the Certification Task Force on the fiscal year 2011 Chapter Certification Standards was approved.

A task force comprised of volunteers and staff representatives from chapters and the home office developed the 2011 standards over a series of 7 conference call meetings. They reflect the Society's expectations that each chapter bears responsibility for meeting Society-wide standards.

TASK FORCE MEMBERS

- Craig Lynch, National Board of Directors (Task Force Chair)
- Pat Abruzzo, Manager, Special Projects, Field Operations
- Barbara Bernbaum, National Board of Directors
- Jay Gurmankin, Chair's Advisory Council
- Eli Lipcon, Chair's Advisory Council
- Bill MacNally, Chair's Advisory Council
- Dick Mengel, Chapter Relations Committee Member
- Mark Neagli, Southeast Regional Executive Vice President
- Darin Pike, Chair's Advisory Council
- John Scott, East Regional Executive Vice President
- Rich Slifka, National Board of Directors
- Robert Sowinski, National Board of Directors
- Peter Tarricone, National Board of Directors
- Craig Weber, Vice President, Chapter Relations
- Cyndi Zagieboylo, Chief Field Services Officer

Prior to sending the final recommendation to the Chapter Relations Committee, Chapter Presidents were provided a 30-day comment period via Survey Monkey. Those comments resulted in some slight modifications that were incorporated into the final report.

The 2010 Certification Standards are posted on the Intranet under Chapter Management, Organizational Policies/Procedures. They are set forth with changes from the 2010 Standards indicated in **BOLDFACE** and have been aligned with the objectives in the Society's Strategic Response 2011-2015. Information about compliance determination at the conclusion of FY2011 will be distributed within the next 60 days.

Craig Weber
Chapter Operations Vice President
303-698-6116
Craig.weber@nmss.org



CHAPTER PRESIDENTS

Date: 8/20/10

CC: Development

Chapter President's Role in Golden Circle Conference Call Schedule

Action Requested/Deadline: Register by September 10

Conference calls are scheduled to prepare Chapter Presidents for their leadership role of growing or starting a Golden Circle Program in FY2011. The calls will focus on program implementation and integration, developing cross-functional teams, and engaging board members and volunteers in Golden Circle Committees.

These calls have been planned specifically for Chapter Presidents new to Golden Circle; Chapter Presidents involved in the 2010 Golden Circle Pilot Program are welcome to participate in either one of the scheduled calls.

Plan to attend and register for your choice of the following scheduled calls:

Wednesday, September 15, 2010 at 3:00 pm ET, 2:00 pm CT, 1:00 pm MT, 12:00 pm PT to register for this meeting go to:

<https://nmss.webex.com/nmss/j.php?ED=140268797&RG=1&UID=1044169317&RT=MIMxMQ%3D%3D>

Wednesday, September 22, 2010 at 12:00 pm ET, 11:00 am CT, 10:00 am MT, 9:00 am PT to register for this meeting go to:

<https://nmss.webex.com/nmss/j.php?ED=140268917&RG=1&UID=1044168967&RT=MIMxMQ%3D%3D>

For additional information contact:

Susan Goldsmith, National Director, Golden Circle
303-698-6100 ext. 15102

susan.goldsmith@nmss.org



DEVELOPMENT

Date: 8/20/10	CC: Chapter Presidents
	Marketing
<u>Corporate Sponsorship Proposal Templates Now Available on Sharepoint</u>	

The corporate relations team is pleased to announce that new corporate sponsorship proposal templates have been completed and are available for chapter customization and use. Design and development of these branded proposal templates included best practices, design elements and feedback from chapters across the country, as well as additional design work by the home office marketing department.

There are four proposal templates available including Bike MS, Walk MS, Combined Bike and Walk, and a General Non-Event design. All of the templates were designed for local and sponsor specific customization and exist in both PDF and Word versions.

To access the proposal templates, please click on the following link (under the Proposal Templates & Examples SubCategory):
<http://intranet.nmss.org/Topics/Development2/Pages/CorporateDevelopment2.aspx>

For questions regarding corporate relations, please contact Julie Stone Hurley at julie.stone.hurley@nmss.org and (303) 698-6100 x15259 or Becca Kornfeld at becca.kornfeld@nmss.org or (212) 476-0484.



DEVELOPMENT

Date: 8/20/10

CC: Chapter Presidents

FY11 Golden Circle Training Plan

Action Requested/Deadline: Register for 1st session by August 27

Staff training for Golden Circle Program Managers and staff responsible for the Golden Circle program at their chapter or within their region is scheduled in five training modules. Each training module will be offered in 2 or 3 one hour conference calls with WebEx presentations. New and updated Golden Circle Tool Kit sections, templates and resources related to each training module will be available on SharePoint in advance of each of the following training modules:

- I: Get Ready for Golden Circle Week of August 30- September 3
Learn how to implement program objectives and establish cross functional teams for building donor relationships. Understand the Society-wide Golden Circle program calendar and discover the wealth of branded materials and templates available. Links to register for this module are included at the end of this newsheet.
- II. Develop Your Prospect Pool Week of September 13 -17
Learn how to use Golden Circle prospect reports to identify qualified prospects. Discover how the reports will guide your day-to-day program activity and communication with donors and your cross functional team
- III. Get to Know the Prospects Week of September 20-24
Understand how to engage volunteers and establish a Golden Circle Committee to build donor relationships. Learn how to plan Golden Circle events to cultivate, engage and inspire support from your prospects.
- IV. Annual Membership Week of September 27 – October 1
Maximize donor retention and loyalty through annual Golden Circle membership. Use the prospect reports to identify, prepare membership solicitation mailings and welcome prospects as members.
- V. Personal Asks Week of January 17 -21
Identify your top prospects with the capacity and interest in higher levels of support. Learn the moves management process to guide you to confident personal asks.

There are 3 calls planned for the first training module, Get Ready for Golden Circle. Each call is offered at two different times on the scheduled day. Please register for the sessions that best fit your schedule, by August 27 using the links below:

Session I: Understand and implement Golden Circle objectives, the annual program calendar and branded materials.

Tuesday, August 31: 12 – 1pm ET, 11am -12pm CT, 10 – 11am MT, 9-10am PT

<https://nmss.webex.com/nmss/j.php?ED=140294967&RG=1&UID=1044221542&RT=MIMxMQ%3D%3D>

OR 3 – 4pm ET, 2-3 pm CT, 1 - 2 pm MT, 12-1pm PT

<https://nmss.webex.com/nmss/j.php?ED=140295622&RG=1&UID=1044223382&RT=MIMxMQ%3D%3D>

Session II: Establish a cross functional staff team supporting the Golden Circle program.

Wednesday, September 1: 11-12 am ET, 10-11am CT, 9 -10 am MT, 8 – 9 am PT

<https://nmss.webex.com/nmss/j.php?ED=140296057&RG=1&UID=1044224137&RT=MIMxMQ%3D%3D>

OR 4-5 pm ET, 3-4 pm CT, 2-3 pm MT, 1-2 pm PT

<https://nmss.webex.com/nmss/j.php?ED=140296147&RG=1&UID=1044224222&RT=MIMxMQ%3D%3D>

Session III: Basics of starting and building relationships with donors

Thursday, September 2: 1-2pm ET, 12-1 pm CT, 11am -12pm MT, 10-11am PT

<https://nmss.webex.com/nmss/j.php?ED=140296232&RG=1&UID=1044224332&RT=MIMxMQ%3D%3D>

OR 4-5 pm ET, 3-4 pm CT, 2-3 pm MT, 1-2 pm PT

<https://nmss.webex.com/nmss/j.php?ED=140296297&RG=1&UID=1044224432&RT=MIMxMQ%3D%3D>

For additional information contact:

Susan Goldsmith, National Director, Golden Circle

303-698-6100 ext. 15102

susan.goldsmith@nmss.org



DEVELOPMENT

August 20, 2010

CC: All

Search Marketing Pilot

After a thorough selection process, we are pleased to announce a Society-wide search marketing (Google AdWords) pilot that will be led by a Society-wide team and [EngineWorks](#), an Oregon-based Internet marketing firm that specializes in online search strategy and techniques.

EngineWorks has done project work for the Oregon Chapter and was selected by a Society-wide committee, including representatives from Central Virginia, Greater Northwest, Minnesota, New Jersey Metro, Northern California, Oregon, Pacific South Coast, and Wisconsin. Many thanks to all of the selection committee members for their time and input!

Objectives for the three-month project include, but are not limited to:

- Analysis of the Society's current search marketing presence
- Creation of a Society-wide search marketing strategy, with initial focus on paid per click (PPC) campaigns; objectives include event participant acquisition and general MS awareness
- Integration of local and national search campaigns
- Implementation of robust measurement infrastructure
- Development of training plan that will facilitate Society self-management of PPC campaigns
- Creation, execution and optimization of a pilot project to include a number (tbd) of Bike MS and Walk MS events (objective: participant acquisition)

If you have questions about the project – or if you would like to become involved – please contact any of the following:

Amy Boulas, Walk MS, amy.boulas@nmss.org or 303-689-6100 x15123

Rachael Nuwash, Bike MS, rachael.nuwash@nmss.org or 303-698-6100 x 15136

Rich Sarko, Online Marketing, rich.sarko@nmss.org or 303-698-6100 x 15171



PROGRAMS & SERVICES

August 20, 2010	CC:
<u>Client Publications Update</u>	

A document titled, “[Publications Updates And Advisories](#)” is on SharePoint (Programs & Services>Education Resources for People with MS > Publications) and lists the current version of each client publication. It also lists discontinued pubs and redesign status. This list is updated every few months. There are only a couple publications that have not been redesigned and are okay to continue to use (as noted); otherwise, any that still have the red logo should be discarded.

Client Publications can be found on our Web site at www.nationalMSSociety.org/brochures. They are listed by subject matter or by title only. The majority of publications are available in print format, and they are all available online in PDF format. In an effort to save on printing and postage, we encourage you to refer people to the web site, but always send them hard copies if they prefer.

Chapters may contact chapterorders@nmss.org to order publications. Clients may request hard copies from chapters and IRC.

If you have any questions, please contact Wenda Carlson.

Wenda Carlson
Publications & Project Specialist
Denver Home Office
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303-698-6100, ext. 15152



PROGRAMS & SERVICES

August 20, 2010

CC: Advocacy

Chapter Presidents

Health Care Reform Web Ex Training September 16 2010

We have scheduled a Webex training for **September 16 (Thursday) from 3-4pm ET (2-3pm CT, 1-2pm MT, noon-1pm PT)** for chapter service managers, advocacy staff and others interested in learning more about ‘The Affordable Care Act’ (ACA, health care reform) and how some of the early benefits of the law could impact people with MS. On the call, we will highlight some of the newly-implemented aspects of the ACA and their implications for the MS community, how the IRC is responding to inquiries about health care reform, and the law’s implementation schedule. We also hope to gather some personal stories about how the Act is affecting our clients-- to use for education and awareness activities.

As you know, the Affordable Care Act puts into place comprehensive health insurance reforms to make health coverage more accessible and affordable for everyone, insurance companies more accountable, enhance the quality of care and reduce the rate of cost growth. People with MS may be particularly affected by the new expansions in coverage, caps on costs and other consumer protections. It is also very comprehensive and designed to be phased-in over many years. For that reason, this training opportunity will be the first in a series. It is helpful for MS Navigators to have a basic understanding of the various aspects of the law and to be able to guide clients to the appropriate resources.

The presenters on the call will be: Kim Calder, Director-Federal Health Affairs & Insurance Policy, Sharon O’Hara, VP- Programs and Services (Colorado Chapter), Erica Keinhoff, Programs Manager (Mid America Chapter) and Kris Erikson, Health Insurance Manager (IRC). There will be time for questions and discussion. If you have suggestions for specific aspects of health care reform that you would like to see addressed during this training or if you have other questions, please contact Kim Calder at 212-476-0450. Please pre-register by clicking on this link:

<https://nmss.webex.com/mw03061/mywebex/default.do?siteurl=nmss&service=7;>

Click on the “upcoming” tab along the top, and then scroll down to find: “Health Care Reform Service Management Training”; September 16. The dial-in information is: 1-866-417-3327; Conference Code: 138 427 5512. *We strongly encourage at least one person per chapter to attend.* Kim Calder, Director-Federal Health Affairs & Insurance Policy 212-476-0450; kim.calder@nmss.org



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RESEARCH/CLINICAL UPDATE

August 20, 2010

MS Trial Alert:

Investigators Studying ELND002, Subcutaneous Drug in 125 People with Relapsing MS

Summary: Investigators are recruiting 125 people with relapsing MS in the United States and Canada to determine the safety and effectiveness of ELND002, a variation of an alpha-4-integrin inhibitor delivered via injection under the skin. Elan Pharmaceuticals is sponsoring the study.

Rationale: ELND002 is thought to work by preventing certain white blood cells (called mononuclear leukocytes) from entering the central nervous system. Blocking these cells may prevent the inflammation associated with disease activity in MS. The exact mechanism of action is not known. ELND002 is a “pegylated” molecule that is delivered via subcutaneous injection, rather than in-vein infusion. Pegylated molecules are attached to a molecule of polyethylene glycol, which enables them to maintain effects in the body for longer periods of time. ELND002 is hypothesized to be a selective inhibitor of alpha-4 integrin. Further studies are needed to support this hypothesis.

Eligibility and Details: Participants will have relapsing forms of MS (<http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/index.aspx>) with documented medical history of relapse in the past year or MRI-documented evidence of MS activity in the past year. Excluding criteria include a positive test for the JC virus DNA in plasma (which causes PML). Further information on the detailed inclusion and exclusion criteria are available from the contact below.

One hundred participants are being randomly assigned to receive escalating doses of the study drug, and 25 are being assigned to receive inactive placebo, for a period of 12 weeks. All participants will also be followed for one year thereafter. The primary objective is to determine the safety and tolerability of ELND002 and to determine the maximum tolerated dose.

Secondary objectives include the compound's effectiveness at reducing disease activity on MRI and relapse rates.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please contact Darcy Forman at (919) 678 4603; darcy.forman@i3research.com; or ms@dandersoncompany.com.

Sites are recruiting in the following cities:

Cordova, TN
Newport Beach, CA
Montreal, QC
San Antonio, TX
Fresno, CA
Raleigh, NC
Tampa, FL
Berkeley, CA
Albuquerque, NM
Knoxville, TN
Greenfield Park, Quebec
Cincinnati, OH
Teaneck, NJ
Farmington Hills, MI
Vero Beach, FL
Uniontown, OH
Minneapolis, MN
Aurora, CO
Salt Lake City, UT
Northbrook, IL
Calgary, Alberta
Vancouver, BC

[Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial \(PDF\).](#)

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RESEARCH/CLINICAL UPDATE

August 20, 2010

MS Trial Alert:

Investigators in Alabama Seeking Participants for Physical Therapy Study in MS

Summary: Investigators at the University of Alabama at Birmingham are recruiting 66 people with relapsing-remitting, secondary-progressive, or primary-progressive MS (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/what-is-ms/four-disease-courses-of-ms/index.aspx>) to participate in a study comparing the effectiveness of two types of physical therapy for increasing movement (improving nonuse) of the arm in MS. This study (<http://www.uabhealth.org/13246/>) is funded by the National MS Society and the National Institutes of Health. **Please note: the study requires 12 to 14 visits to the site in Alabama, including 10 consecutive days of treatment and 1-2 days for pre- and post-treatment evaluations.**

Rationale: MS can cause reduced use of a person's arm even if there is still enough ability to perform daily living activities. This lack of use is called "learned nonuse." Certain forms of physical therapy have been shown to improve this condition in other neurological disorders (such as stroke and cerebral palsy), but the treatment of learned nonuse in MS has not been well studied. This study will compare two different physical therapy approaches to determine whether learned nonuse can improve in MS.

Eligibility and Details: Participants will be people with relapsing-remitting, secondary-progressive, or primary-progressive MS, who have not experienced a relapse for at least the past three months.

Individuals will be randomly assigned to receive either constraint-induced movement therapy (a concentrated form of physical therapy directed at the more impaired arm) or a program of complementary and alternative medicine techniques including aquatic therapy, relaxation exercises, massage, and music therapy. Each program will consist of 3.5 hours of therapy per day for 10 consecutive weekdays.

The primary outcome being measured is a Motor Activity Log that will be completed before treatment, and immediately, six months, and 12 months after the end of treatment. Secondary measures include other clinical scales measuring disease activity, arm function, and quality of life. In addition, this study will measure whether either form of treatment significantly changes brain structure on MRI scans before and after treatment.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please call Mary Bowman or Staci McKay at (205) 975-2177 or (205) 934-9768; or e-mail Victor Mark, MD, at vwmark@uab.edu. More information is available at <http://www.uabhealth.org/13246/>.

Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial (PDF). (<http://www.nationalmssociety.org/research/clinical-trials/download.aspx?id=2583>)