

# CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Volume 2 • Issue 4

Maine Chapter

## Women Against MS

March 12, 2008  
Holiday Inn by the Bay, Portland  
Featuring keynote speaker  
Sue Thomas  
Hosted by WGME news anchor  
Kim Block



Join us for the Portland Women Against MS Luncheon and help us celebrate MS Awareness Week. Mark your calendar for Wednesday, March 12, 2007 at the Holiday Inn

by the Bay for this exciting event benefiting the Maine Chapter, National MS Society. The Women Against MS (WAMS) Luncheon is a leadership initiative designed to bring women and men together in the fight against multiple sclerosis. This year's guest speaker, author, television personality and MS Ambassador, Sue Thomas, will inspire the hundreds of attendees with her compelling story and remarkable achievements.

Sue was diagnosed with loss of hearing at eighteen months. "I've worked all my life to function in the hearing world," she says, noting that her hard work finally paid off

when she was hired by the Federal Bureau of Investigation in Washington, DC. At first, she helped start a program to train deaf people to classify fingerprints. However, due to her superb ability to read lips, she was approached by agents who had videotaped an investigation, only to find the camera's sound mechanism had failed. "They asked if I could read the people's lips and tell what was being said."

Her successful completion of that high profile case led to work in undercover surveillance. "It was no problem for me to stand across a room in, say, an airport where a deal was going down, and take verbatim notes on what the suspects were saying!"

Sue's adventures with the F.B.I. have been dramatized in the PAX Television series titled, Sue Thomas: F.B.Eye.

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## Call to Action

If you or Someone You Know Has MS Studies show that early and ongoing treatment with an FDA-approved therapy can reduce future disease activity and improve quality of life for many people with multiple sclerosis. Talk to your health care professional or contact the National MS Society at [www.nationalmssociety.org](http://www.nationalmssociety.org) or 1-800-344-4867 to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

Information provided by the Society is based upon professional advice, published experience and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The National Multiple Sclerosis Society recommends that all questions and information be discussed with a personal physician. The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability for the use or contents of any product or service mentioned.

## How to Reach Us:

Maine Chapter 170 US Route One, Ste. 200 Falmouth, ME 04105 Tel: 1-800-344-4867 Fax: 207-781-7961 Website: <a href="http://www.msmaine.org">www.msmaine.org</a> E-Mail: <a href="mailto:info@msmaine.org">info@msmaine.org</a>	Outreach Office: 40 Harlow St. Bangor, ME 04401 Tel: 1-800-344-4867 Fax: 207-942-3548 <a href="mailto:heastman@msmaine.org">heastman@msmaine.org</a>
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The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS.

## Chapter Staff

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**Ross Berger**-Finance & Operations Assistant

**Traci Chenette**-Care Management Coordinator

**Mufalo Chitam**-Special Events Manager

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**Heidi Eastman**-Program Coordinator

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**FROM COVER**

At 51, Sue faced another roadblock when she was diagnosed with multiple sclerosis. While on her way to a speaking engagement in Dallas, she felt numbness in her fingers that spread up her wrist to the side of her head. In front of 7,000 people, with only her publicist knowing about the numbness, Thomas completed the speaking engagement that day.

Join us at the 2008 Women Against MS Luncheon on March 12th as we celebrate MS Awareness Week (March 10 – 14, 2008) and hear Sue’s inspirational message about not only overcoming but excelling despite living with two disabilities.



Award winning WGME/ Channel 13 news anchor Kim Block will be hosting the 2008 WAMS Luncheon. Through the years Kim has covered many of Maine’s most significant news stories, interviewed prominent

state figures and has found her niche in medical/health reporting as WGME News 13’s Healthy Living reporter.

WAMS Committee members include Ellie Baker, Kim Block, Jackie Collard, Maddy Corson, Dorothy Eckhardt, Jill Frame, Mary Fuller, Nancy Mackin, Suzanne Dubois and Karen Wood. WAMS Advisory Committee members include Judy Horan, Mary Jalbert, Catherine Lamson, Amy Littell, Amy Morse and Gail Roppo.

Nearly one in every 400 people in Maine has MS. Approximately 75% of people with MS in Maine are women. In fact, Maine has one of the highest incidences of MS in the country – approximately 70% higher than

the rest of the nation. And every hour of every day someone new will be diagnosed with this unpredictable disease. The Maine Chapter of the National MS Society is proud to offer the WAMS Luncheon as a way for Mainers to take the lead in ending the devastating effects of MS. MS stops people from moving. The National MS Society exists to make sure it doesn’t. Please help us in our quest to end the devastating effects of MS and support the 2008 WAMS Luncheon.

For sponsorship and ticket information, please contact Michelle Zichella at (207)781-7960 or [mzichella@msmaine.org](mailto:mzichella@msmaine.org). Please check our website at [www.msmaine.org](http://www.msmaine.org) for news and updates about the 2008 Women Against MS program.

**walk MS:  
Manpower Maine Walk**

Jane Newcomb describes the MS walks like this: “The MS walks are very important to me because they give me hope and they allow me to be a part of a group working towards a very positive goal”. Join the walk MS: Manpower Maine Walk and become part of this group for the annual walk at one of 12 walk sites.

The National MS Society, Maine Chapter believes that moving is not just something you can or can’t do, but rather is who you are. This is why we sponsor events like walk MS: Manpower Maine Walk —to raise funds for research, as well as comprehensive programs

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and services for people with MS moving closer to a world free of MS. Join nearly 4,000 walkers and volunteers for a fun and friendly community oriented 3-5 mile walk and enjoy a wonderful finish line celebration filled with food, drinks and great entertainment.

## Walk Site Locations

### April 12, 2008 except for Caribou and Eastport

#### Augusta: Togus Veterans Admin. Medical Center

One VA Center, Augusta, ME 04330  
LONG - 5 MILES SHORT- 1 MILE

#### Androscoggin County: Lewiston High School

156 East Ave, Lewiston, ME 04240  
LONG - 5 MILES SHORT- 1 MILE

#### Brewer/Bangor: Brewer Auditorium

318 Wilson St, Brewer, ME 04412  
LONG - 5 MILES SHORT- 1 MILE

#### Brunswick: Brunswick Junior High School

165 Columbia Ave, Brunswick, ME 04011  
LONG - 5 MILES SHORT- 2.5 MILES

#### Camden/Midcoast: Camden Rockport Middle School

34 Knowlton St, Camden, ME 04843  
LONG - 5 MILES SHORT- 1 MILE  
New Walk Site!!

#### Caribou April 26: Cary Medical Center

163 Van Buren Road, Caribou, ME 04736  
LONG - 5 MILES SHORT- 2.3 MILES

#### Eastport MAY 4: Eastport Youth Center

Broad Cove Rd, Eastport, ME 04631  
LONG - 5 MILES SHORT- 2.5 MILES



**Russ Anderson, Chapter President and Doug McKeown, CEO, Woodard & Curran**

#### Ellsworth: Ellsworth Middle School

20 Forrest Ave, Ellsworth, ME 04605  
LONG - 3.5 MILES SHORT- 2.5 MILES

#### Greater Portland: Scarborough High School

20 Gorham Rd, Scarborough, ME 04074  
LONG - 6.6 MILES SHORT- 1 MILE

#### Kennebunk: TBA

LONG - 5 MILES SHORT- 1 MILE

#### Sanford: Sanford High School

52 Sanford High School Blvd, Sanford, ME 04073  
LONG - 5.3 MILES SHORT- 2.4 MILES  
New Walk Site!!

#### Waterville: Waterville High School

1 Brooklyn Avenue, Waterville, ME 04901  
LONG - 5 MILES SHORT- 2.5 MILES

Join the Movement! Register to walk or volunteer at [www.msmaine.org](http://www.msmaine.org) Email [walkinfo@msmaine.org](mailto:walkinfo@msmaine.org) or call 1-800-344-4867

For more information, call Mufalo Chitam: 1-800-526-8890  
Email [mchitam@msmaine.org](mailto:mchitam@msmaine.org)

## What is CIS?

A person diagnosed with CIS, or Clinically Isolated Syndrome, typically has experienced a single neurological symptom, such as partial vision loss, vertigo, double vision, or weakness. The symptom lasts at least 24 hours and may even continue for weeks, but then goes away, often without treatment.



“[CIS] typically occurs out of the blue in an otherwise healthy person,” said J. Theodore Phillips, MD, PhD, director of the MS Center at Texas Neurology in Dallas. “It appears to be occurring in an isolated fashion.” To be diagnosed with CIS, all other explanations for the symptom have to be ruled out.

### Is CIS an early sign of MS?

The big question with CIS is whether it indicates early development of MS. The second question is whether early intervention can help slow down that development. In three large clinical trials, early treatment appeared to delay a second episode. The results were so positive, the FDA extended the labeling of Avonex and Betaseron to include people who have had just one clinical episode if they have multiple MRI-detected lesions consistent with MS.

### Is early intervention necessary?

“If started early in the appropriate person, these medications can be important in slowing down the progression into classic MS,” Dr. Phillips said. “But who is the appropriate person? Do I know that this

single event will evolve into MS?” Disease-modifying drugs are expensive, inconvenient, and do not cure MS, he pointed out.

### MRI evidence makes the case

Long-term studies show that what a person’s MRI looked like at the time of a CIS largely indicated whether they went on to develop MS.

“If the MRI is completely normal with the exception of abnormality associated with the CIS, then that person has a relatively low risk of MS even 15 years out,” said Dr. Phillips. “But if there are multiple lesions consistent with MS, that person has a pretty high risk.” When that’s the case, many neurologists recommend early intervention with a disease-modifying drug. Insurance coverage for Avonex or Betaseron shouldn’t be a problem, since the FDA now includes CIS as an indication for both drugs.

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 — Janet Z. (Dunbarton, NH)

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## MS Caucus gains power

This summer the Society announced the new Congressional Multiple Sclerosis Caucus in the U.S. House of Representatives. This Caucus is the first of its kind, and provides the MS movement with champions in Congress to support MS issues. Congressmen Russ Carnahan (D, Missouri) and Michael Burgess (R, Texas) are co-chairing. As of late September, 38 members have joined. (For the current list, visit [msactivist.blogspot.com](http://msactivist.blogspot.com).)



Congressman Russ Carnahan



Congressman Michael Burgess

### Keep the momentum building

The MS Caucus gives the movement to end MS an effective presence on Capitol Hill. If your U.S. Representative has not yet signed on, encourage him or her to do so. Go to [nationalmssociety.org/advocacy](http://nationalmssociety.org/advocacy), click on **Announcing New Congressional MS Caucus**, and enter your ZIP Code.

## The push for new MS research funding

For the past year, the Society and thousands of MS activists have been aggressively pursuing a new avenue of federal funding for MS research: Legislation that would designate \$15 million for MS research through the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense.

Unfortunately, the bill that passed in the House on August 5, 2007, did not include funding for MS research. But MS activists did not give up. In late September, Congressman John Murtha (D, Pennsylvania) finally agreed to fight for at least \$10 million for MS research during the conference committee, which came after the Senate voted on the bill.

When the Senate Defense Appropriations Subcommittee approved their FY 2008 spending in mid-September, the bill included language to support MS research. Even though it was not in the program we requested, it will provide a new avenue for funding. We will continue pursuing CDMRP.

### About the funds

The CDMRP provides funding for research through the Department of Defense as directed by members of Congress. Activists believe that MS research would be an appropriate target of these funds: A study published in 2004 identified more than 5,000 cases of MS among veterans that were deemed "service-connected."

In late 2006, the Society began a nationwide petition drive urging Congress to support funding for MS research through the CDMRP. The petition garnered more than 100,000 signatures.

In March 2007, MS activists who attended the annual MS Public Policy Conference in Washington, DC, brought the issue to Capitol Hill in person.

### What's next

For the latest, go to [msactivist.blogspot.com](http://msactivist.blogspot.com), and to learn how to help, join the movement at [nationalmssociety.org/advocacy](http://nationalmssociety.org/advocacy).

## Society-funded researchers discover two new “MS risk” genes

**M**S is not a single-gene disorder. Researchers have already concluded that the disease involves many genes interacting with some environmental trigger or triggers.

Locating the specific genes that are associated with a higher risk for MS can tell scientists more about how the disease works—and may lead to new therapies.

For more than a decade, the National MS Society has taken the lead, aggressively

funding MS genetics research. It helped launch the International Multiple Sclerosis Genetics Consortium (IMSGC), a collaborative group of researchers with expertise

in genetics, database design, and immunology who pool the large amounts of data needed for genetics studies.

### New findings

This year, the IMSGC completed the largest genome scan for MS to date. Using a DNA chip that maps 500,000 individual genetic locations they found two genetic variations strongly associated with MS.

The variations were found in the genes for **interleukin-2 receptor-alpha** and **interleukin-7 receptor-alpha**, both of which control **cytokines**—the messenger

proteins that regulate immune cells. Interleukin-2 and -7 have been associated with T cells that have the power to turn off an immune attack. Research has shown that interleukin-2 is involved in other auto-immune diseases, including type 1 diabetes.

The IMSGC published these findings in an early online edition of **The New England Journal of Medicine** (July 29, 2007). The study was jointly funded by the Society and Harvard University. All of the data from the gene scan is being made publicly available to aid future research.

### Two studies confirm findings

Two papers published online in **Nature Genetics** on July 29 reported similar findings associating interleukin-7 with MS.

In the first, an international group of collaborators funded in part by the Society explored three genes that had earlier been associated with MS. The group was able to confirm an association with the gene for interleukin-7.

The second paper—by collaborators in Sweden, Denmark, Finland, and Norway—followed up an earlier study and also identified interleukin-7.

### The road ahead

The findings of all three studies suggest possible new targets for better MS therapies. One therapy is already being tested. The monoclonal antibody “daclizumab” (PDL BioPharma and Biogen Idec) targets interleukin-2 receptor-alpha.



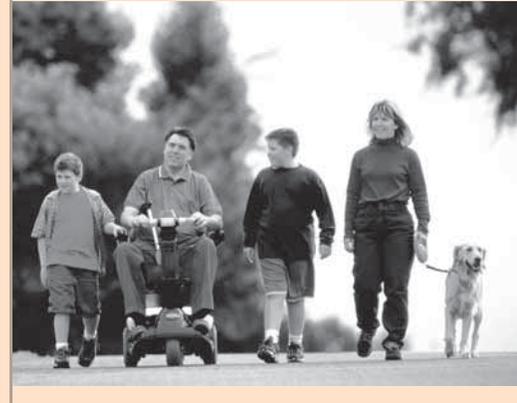
# Some plain talk about life insurance

Kim Calder, MPS

## Can a person with MS purchase life insurance?

This is one of many insurance-related questions that may arise after a diagnosis of MS. The facts provide a somewhat mixed outlook for those who hope to include life insurance in their personal financial plans.

A survey of Society members living with MS conducted last year revealed that nearly 70% have a life insurance policy, although most of them obtained it prior to diagnosis. Slightly more than half of those who tried to get life insurance for the first time after diagnosis were turned down. But among those who obtained it after diagnosis, 70.1% reported no difficulty in purchasing it. About 16% reported being charged a higher rate because of MS and 20% said their coverage was limited due to their disease. (It is not known if the applicants who were turned down were different from those who were accepted. Were they older, for example, or more severely disabled? )



Risk is a complicated concept, because it relies on averages. A few people with MS who develop very progressive disease die prematurely of its complications (such as respiratory infections, for example). Thus overall life expectancy in MS is considered to be 95% of normal. Insurance companies give their best policy terms to the “best bets”—to people who are in perfect health. But that doesn’t mean a person with MS can’t obtain a policy, as our research showed. Here are some general tips for shopping for life insurance:

- Maximize your opportunities to obtain life insurance through your own or your spouse’s employer. (Your spouse should do the same!)
- An insurance broker could save you a lot of time and frustration. Call an MS Navigator at our chapter to help you find one.

- Apply for life insurance as early in your disease process as possible, before MS has a chance to impair your functioning any further.
- Never try to hide your diagnosis from an insurance company or a broker working on your behalf. Failure to disclose any requested information is fraud, which could bring very severe (even criminal) penalties.
- If you are not satisfied with the offers you receive, keep searching.

If you are ultimately unable to purchase the life insurance coverage you are looking for, a good financial planner may be able to suggest other strategies to help you reach your financial goals and provide protection for your future. Ask your MS Navigator to help you identify a financial planner with whom you can review all the issues.

## ~ Programs for People Newly Diagnosed with MS ~

### **Can We Talk? A Teleconference Series for People who have Recently Been Diagnosed with MS**

Do you want to learn about topics of interest to people newly diagnosed with MS from experts in their field? Ask questions, receive information, and get support. These conference calls are toll-free and are open to anyone diagnosed with MS, within the last three years, and family members or friends. Teleconferencing is a convenient and interactive way to obtain information from the comfort of your home. All you need is a phone!

Date: March 4, 2008  
 Time: 7:00pm-8:00pm  
 Location: Teleconference

The topic of this teleconference is: MS: Insurance Options & Money Matters

Date: April 1, 2008  
 Time: 7:00pm-8:00pm  
 Location: Teleconference

The topic of this teleconference is: Exercise and Fatigue

### **Newly Diagnosed Dinner**

Date: March, TBD  
 Time: TBD  
 Location: Portland, TBD

Join the Maine Chapter for a relaxing evening to network and socialize with other people who have recently been diagnosed with MS. This is an opportunity to meet people, and learn about the programs and services available through the Maine Chapter.

## ~ Special Programs ~

### **Women's Program: The Three M's**

Date: February, TBD  
 Time: TBD  
 Location: Augusta, TBD

Enjoy a workshop devoted to issues specific to women living with MS. The program will feature sessions on Mood, Motherhood, and Menopause! This program is a perfect fit for women who are trying to balance it all with a positive outlook and enough energy to enjoy being a woman while living with MS! Additional sessions will focus on women who are interested in becoming pregnant, women who already have children, and women entering menopause.

### **Progressive MS**

Date: April, TBD  
 Time: TBD  
 Location: Bangor, TBD

This program is designed to offer insight and tips to people living with Progressive MS. Enjoy consultations with Occupational and Physical Therapists, explore complementary therapy options, and discover what sort of assistive technologies can enhance your independence and quality of life. We are still in the preliminary stages of planning this program. If you are living with Progressive MS, contact the Maine Chapter to let us know what you are interested in getting out of a program like this!

## ~ Ongoing Programs ~

### **Financial Assistance Program**

The FY08 Financial Assistance Program has resumed. For this year's application, call 1-800-344-4867, Select Option 1, or download an application from our website.

### **MS Buddies/Peer Support Program**

The MS Buddies program links participants with volunteer "Buddies" to provide consistent, short-term, one-on-one peer support. An MS Buddy is simply someone for you to talk to who can understand what you are going through. This program is perfect for people who are newly diagnosed, or those in transition who can benefit from one-on-one support as a part of their overall support system.

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**Adaptive Aquatics - Southern Maine**

Aquatic exercise allows people to do strength training and stretching; this class is taught by someone with specific training in MS. Classes are held at John Richard's Pool in Cape Elizabeth on Tuesdays and Thursdays from 1-2pm. To register, call Karen at 799-2868.

**Adaptive Yoga**

Date: Every Thursday  
Time: 10:00am  
Location: TBD

Contact yoga instructor Bunny Barclay, 989-9730, to register for this weekly yoga class. Cost is \$2/session.

## Self-Help Group Listing: January-March

**S**elf-Help Groups bring together people who share a common life experience for support, education and mutual aid. Each group has its own personality and focus. If you're not enjoying the friendship and support of a peer group, consider contacting a group facilitator in your area to learn more about self-help groups for people with MS and their care partners.

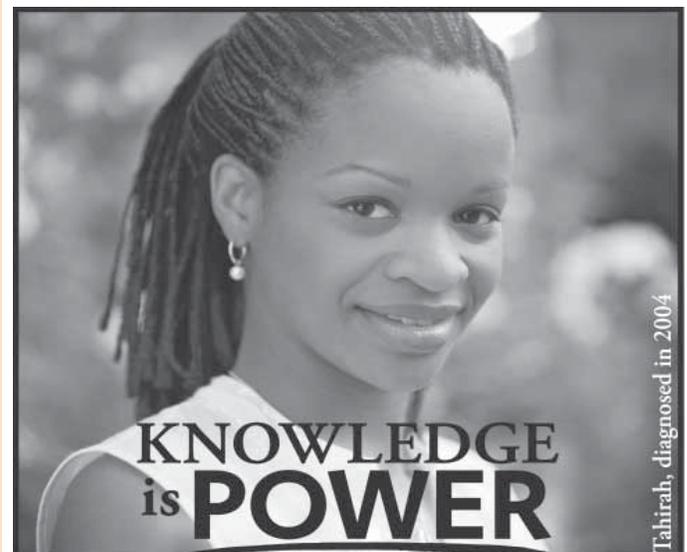
For a complete list of Self-Help Group meeting schedules and contact information, please visit our website at [www.msmaine.org](http://www.msmaine.org), or call 1-800-344-4867 (Select Option 1) for more information about the following groups:

Augusta	Mid-Coast (Rockland)
Belfast	Millinocket Area
Bethel	Rumford
Brunswick	Sanford
Caribou	Scarborough
Ellsworth	South Portland
Falmouth	York
Lewiston/Auburn	

### Important Notes Regarding Self-Help Groups:

- For any and all presentations made by individuals or organizations at support groups: The National MS Society respects the rights of people with MS to obtain

any and all information they want related to MS, including information on wellness, medical treatments or complementary therapies, and products and services. The information presented at meetings does not necessarily reflect the view or official position of the Society, nor carry the endorsement or support of the NMSS.



**Knowledge Is Power** is a six-week, free, at-home educational program for people who are newly diagnosed. Mail or e-mail formats. To register, call **1-800-344-4867**, or visit [nationalmssociety.org/knowledge](http://nationalmssociety.org/knowledge).

This is why we're here.



## Staff Additions & Promotions!

**T**he Maine Chapter welcomes Traci Chenette, LCSW. Traci is the Chapter's Care Management Coordinator and will be working with people with multiple sclerosis on a 1:1 basis. She will also be supporting many of the Chapter Self Help Groups as well as the Peer Support Program. Traci has her Masters in Social Work as well as her license as a Clinical Social Worker. She has several years of Case Management experience. We are excited to welcome Traci to the Chapter in this new position.



We are proud to announce a new addition to the special events staff, Heather Orlando. Heather joined the chapter in May 2004 as office manager and has shown great dedication to the chapter and its mission. In her new position as Special Events Coordinator, Heather's focus will be on leading the bike MS event. Heather will also play a key role in other chapter events.

We are pleased to announce that Mufalo Chitam has recently been promoted to Special Events Manager. Mufalo joined the Maine Chapter in October 2005 as our Special Events Coordinator. Since then she has coordinated walk MS and Plane Pull. In her new position Mufalo will manage these events and will continue to work on other Chapter events.

### 2007 Annual Meeting

The Maine Chapter welcomed new Board Members and recognized volunteers and supporters of the Chapter at the 2007 Annual Meeting.

The Maine Chapter held the 2007 Annual Meeting on Thursday, November 29th, 2007. Dr. Ellen Lathi gave a keynote address to attendees, and provided a glimpse into current and upcoming research in MS. Awards were presented to volunteers and dedicated members of the Maine Chapter, as well as sponsors from

the 2007 Fiscal Year. Mary Jalbert, Treasurer of the Board of Trustees, presented the Chapter's 2007 financial results. The Maine Chapter Board of Trustees was elected at the Annual Meeting as well. New members of the Board include John Edwards of Bangor Savings Bank and Charlie Tarbell of Disability RMS. The 2008 Officers are as follows:

- Gail Roppo , Board Chair
- Jacqueline Collard, Vice Chair
- Mary E. Jalbert , Treasurer
- Catherine Lamson, Secretary

Save The Date!

# Women Against MS

walk

March 12th, 2008

bike



Presented By:

Verrill Dana LLP  
Attorneys at Law



walk to  
create a world  
free of MS

April 12th, 2008

August 14th - 17th, 2008



bike to  
create a world  
free of MS

August 2nd & 3rd, 2008

September 6, 2008

## 2008 MS Awareness Week

**M**ark your calendars! The National MS Society will recognize MS Awareness Week March 10-14, 2008. The Maine Chapter is currently planning awareness activities for the week. One of our most visible MS Awareness Week events will

be the Women Against MS Luncheon to be held in Portland on March 12th from 12:00pm-1:30pm. Please join the chapter in recognizing MS Awareness Week. Plan awareness activities in your community and encourage everyone to Join the Movement!

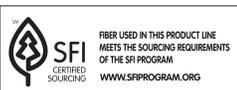


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Maine Chapter  
170 US Route One  
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[www.msmaine.org](http://www.msmaine.org)

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