National Multiple Sclerosis Society

CONNECTION

MOVING TOWARD A WORLD FREE OF MS

Volume 4 • Issue 1 Maine Chapter

bike MS: Saint Joseph's College Bike to the Breakwater is not just for cyclists anymore!

bike MS

Bike to the Breakwater 2008

The 2nd Annual Bike to the Breakwater Wellness Expo

Indulge your mind, body and spirit at the bike MS: Bike to the Breakwater 2008 Wellness Expo! This event will take place on Saturday August 2, 2008 during the Maine Chapter's annual bike MS: Bike to the Breakwater from 10am to 4pm.

Every client, cyclist and volunteer is welcome to join us for the bike MS: *Bike to the Breakwater* 2008 Wellness Expo presented by UNUM. This one day event gives attendees the opportunity to experience products and services such as free health screenings, massage therapy, yoga demonstrations, natural skincare products, healthy and organic food options, aromatherapy, cycling products, and much more!

This event will offer exhibitors a terrific opportunity to showcase products and services to more than 1,000 cyclists, volunteers, clients and their families who come through the campus the weekend of bike MS. If you would like more information on becoming an exhibitor contact Hannah Montgomery at 1-800-526-8890 or email hannah.montgomery@nmss.org.

Volunteer at bike MS!

Wondering how you can get more involved in creating a world free of MS? The bike MS event is always looking for volunteers to Join the Movement in any capacity. You can help manage a rest stop, mark a route for participants, make and/or serve lunch, cheer on incoming riders at the finish line or work the registration table. The opportunities are endless! Learn more about specific responsibilities call Mufalo at 1-800-526-8890 or email mufalo.chitam@nmss.org.

Bike MS: *Bike to the Breakwater* will take place on August 2nd & 3rd, 2008. There is plenty of room to help us move closer to a cure for MS by participating as a cyclist. For more information on bike MS please call Heather Orlando at 1-800-526-8890 or visit www.msmaine.org.

The funds raised through bike MS: Bike to the Breakwater are crucial to fund research and comprehensive programs and services for people with MS.

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 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: www.msmaine.org
E-Mail: mainegeneralinfo@nmss.org

Outreach Office:

40 Harlow St.
Bangor, ME 04401
Tel: 1-800-344-4867
Fax: 207-942-3548
heidi.eastman@nmss.org

The mission of the National Multiple Sclerosis Society is to end the devastating effects of MS.

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The Art of Asking Help

by Allison Shadday, LCSW

When I first learned I had MS, I was a medical social worker. It was my job to care for people who were ill. I knew how to give others my help, but not how to receive it. Requiring assistance, at any level, can radically alter our sense of independence. It makes us feel so vulnerable! **These tips may make reaching out a little easier:**

- Explore how you feel about needing and asking for help.
- Ask yourself how it feels to help others.
- Recognize that when you ask for assistance, you're giving someone a chance to feel useful.
- Plan on what to ask for when someone says, "Is there anything I can do?" Requests could be as simple as asking someone to go with you to a doctor's appointment.
- Identify at least three people you can call. It's important not to rely on one person for all needs.
- When folks come through for you, show your appreciation.
- Find ways to reciprocate. Let people know that you're there for them as well.

Some benefits of asking for help

- Others gain a better understanding of what you're experiencing.
- It can help you to feel less alone.
- You will have more time for the things that can only be done by you.
- You may have energy for things you would really like to do.

Asking For Help is Not Easy...

But no one should have to face MS alone. If you need assistance navigating the challenges of MS please call the MS Society at 1-800-344-4867. We have staff here in Maine that can help with understanding a diagnosis of MS, treatment options and symptom management strategies, accessing health care, meeting workplace challenges, understanding benefits like health insurance, facing financial challenges and future planning, facing caregiver challenges, and managing life changes. Reaching out can be difficult, but there is help available for people with MS

Tax rebate includes low income people

This May, the IRS begins sending out "economic stimulus" rebates to everyone who filed a federal tax return form for 2007. People on Social Security, disabled vets, and those who have incomes of $3,000 or more a year will receive **$300 for individuals** or **$600 for couples**, even if they haven't filed before.

While the tax filing deadline is April 15, there is no penalty for filing late if you do not owe anything. **And you don't get a check without filing.** File by October 15, 2008.

Visit **irs.gov** or call 800-829-3676 for more information and a copy of the form.

Research needs brain tissue

Brain tissue research has the potential to tell us more about MS—from what causes it to how to prevent it. But less than 1% of people with MS make arrangements for a posthumous donation of brain tissue—not enough for researchers to work with. Researchers also need tissue from healthy brains. The Society is supporting a number of tissue and DNA banks throughout the United States.

In February the Society convened the first MS Tissue and DNA Banks Investigators Meeting. Sue Strauss, a marketing expert in the field of organ donation who helped facilitate the meeting, summed up: "As a person with MS, I'm excited to be working to speed up the process of gathering information about the disease, its causes, and its manifestations."

Two important points

1) Tissue must be taken within hours of death to be of use to researchers, so arrangements must be made in advance.
2) There is no disfigurement of the body and funerals can take place promptly.

If you want to make this generous gift, discuss your wish with several family members and sign up with a facility as soon as possible.

Tissue banks:

Rocky Mountain MS Center
Phone: 303-788-4030
Web site: **mscenter.org**

Human Brain and Spinal Fluid Resource Center Neurology Service
Phone: 310-268-3536
Web site: **loni.ucla.edu/uclabrainbank**

Multiple Sclerosis Tissue Repository at University of Illinois at Chicago
Phone: 312-996-5763

Donations for genetic studies

How do we find the genes that make one susceptible to MS? Investigators at the meeting agreed on the need for DNA, especially from Asian Americans, African Americans, Native Americans, and Latinos. A simple blood donation is all it takes. Contact one of the following:

UCSF MS Genetics Group
Phone: 866-MS-GENES (866-674-3637)
Web site: **ucsf.edu/msdb**

Accelerated Cure Project
Phone: 781-487-0008
Web site: **acceleratedcure.org**

Congressional MS Caucus Builds on Achievements

The Congressional MS Caucus in the House of Representatives, which was founded in July 2007 to give the MS movement a greater presence on Capitol Hill, is already impressing Beltway insiders. By November 2007, the caucus cad helped MS researchers gain access to a $50 million Department of Defense medical research fund previously restricted to other diseases.

Now, members of this bipartisan group—along with other members of the House—are signing on to a letter requesting that $15 million be provided to fund MS research through the Congressionally Directed Medical Research Programs. As of this writing, some 80 representatives have signed.

Jill Allen Murray, the policy director for Representative Russ Carnahan (D-MO), helped the Society set up the caucus. Carnahan, along with Representative Michael Burgess, MD (R-TX), are co-chairs for the House MS Caucus.

Senator Byron Dorgan (D-ND) and Senator Orrin Hatch (R-UT) are co-chairing the newly formed Senate MS Caucus. To invite your senator to join, call 800-828-0498 and ask for his or her office. (Visit **nationalmssociety.org/advocacy** for tips on how to phone legislators).

MAINE MS ACTIVISTS TAKE OUR MESSAGE TO CAPITOL HILL

Former Maine Chapter President Russ Anderson, Care Management Coordinator Traci Chenette, and volunteer Marcia Akers took part in the National MS Society Public Policy Conference in Washington DC on May 6-8. Conference attendees took part in education and training on three key issues important to people with MS in preparation to lobby our Maine representatives on Capitol Hill. They asked legislators for support to create an MS Registry that would accurately document cases of MS in the US; to fund MS research through the Congressionally Directed Medical Research Program (CDMRP); and to eliminate the two-year waiting period for Medicare. Russ, Traci and Marcia met with the health care policy staff of Senator Snowe, Senator Collins, and Representative Allen and with Representative Michaud (see photo). The Maine MS Activists were warmly welcomed and able to educate and inform our legislators and their staff about the concerns of people with MS. It was clear that all four of our elected representatives valued our input and appreciated our efforts on behalf of the people living with MS in Maine.

New Leadership Announced for the Maine Chapter, National MS Society

Longtime community leader, Denise Clavette, joins the movement to end multiple sclerosis

The Maine Chapter of the National MS Society has announced that Denise Clavette has been selected as the organization's new chapter president as of June 9. Clavette replaces Russ Anderson, who announced his intention to step down as chapter president earlier this year.

Clavette brings nearly 20 years experience in non-profit and public sector leadership in Maine, most recently as parks and recreation director for the City of Portland. Originally from Fort Kent, she is a lifelong Maine resident and has expertise in growing organizations strategically through community engagement, collaboration and fundraising. "Denise has the right blend of skills to lead our chapter and continue building the MS movement in Maine," says Gail Roppo, board chair of the Maine Chapter of the National MS Society. "Her vision and community knowledge will keep our chapter moving forward and allow us to help even more people impacted by MS in every community throughout Maine.

VOLUNTEERS NEEDED!

MAKE YOUR MARK AGAINST MS!!

Do you have special skills or talents you would like to use to

Join the Movement?

If so, contact Heather Hutchins at Heather.Hutchins@nmss.org
or call 1-800-344-4867 and press option 1

Opportunites are limitless!

You could be our:
Data Entry
Graphic Designer
MS Activist
Program Support
Rest Stop Host/Hostess
Volunteer Engagement Specialist

and MUCH more!

Maine Volunteer Spotlight

Marcia Akers and grandson, Koby, volunteer for the Maine Chapter

One of the many ways that Marcia Akers volunteers for the Maine Chapter is to help educate the public about MS. March 10-17 was MS Awareness Week. As part of the outreach for that week Marcia volunteered to read a wonderful book about MS, "My Grampy Can't Walk" to her grandson, Koby's, 3rd grade class. The class then decided they wanted to have a penny drive to support people with MS. They raised over $90 in pennies!

Koby who is 8, the son of Debra Humason-Fulgham and Stanford Fulgham, and is in the third grade. Koby just participated in his 9th "walk MS". He began "walking" when he was 8 months old. He is now even more involved, is the top fundraiser for his team and is raising money to find a cure for his grandmother's MS.

Marcia volunteers in many ways to support the work of the chapter and people living with MS. This is her 12th year on the Lewiston/Auburn Walk committee. She was a co-leader and leader of her local MS Support Group for 7 years and "loved every minute of it".

Marcia was our first "buddy" and piloted our Buddy Program in 2005. She clearly understood the need for one on one support and saw the need in the people she met who had MS. The chapter began the Peer Support Program shortly after that.

Marcia is a true advocate, reaching out into the Maine community each day. She uses every opportunity to educate people about MS, whether to a group of nurses, to service organizations or to the person she meets casually in her day. Marcia is part of the Chapter's Speaker's Bureau and is an MS Activist. She volunteers at health fairs and at Chapter programs. She has stuffed envelopes and most recently attended our Public Policy Conference in Washington DC.

Marcia is ready to volunteer where needed, but has also learned that when the volunteer fit is not quite right it is important to say "no thank you". In this way the Chapter staff feels comfortable asking and knowing that Marcia will say yes when it is right and no when it isn't. Thank you Marcia and Koby for all you do for people in Maine who are living with MS!

MS HARBORFEST
RACING FOR A CURE ★ 2008

Presented By:
Verrill Dana LLP
Attorneys at Law

Join us August 14th – 17th for the 27th annual MS Harborfest weekend.

MS Harborfest is the largest charity sailing event in New England and a much anticipated annual event on the Portland waterfront. Since its beginning, the MS Harborfest has attracted thousand of sailors, skippers, sponsors, spectators and volunteers who have joined the movement and raised close to $2,000,000 to help find a cure for multiple sclerosis. There's something for everyone with a benefit auction, sailboat regatta, poker run tugboat parade and muster and Shoreside Festival.

Be sure to join the festivities!

Thursday, August 14: MS Benefit Auction
Woodlands Club, Falmouth

Friday, August 15: MS Regatta Skipper's Meeting and Sponsor Reception
Handyboat, Falmouth

Saturday, August 16: MS Sailboat Regatta
Casco Bay; return to Handyboat
MS Powerboat Poker Run
Casco Bay; return to DiMillo's Floating Restaurant

Sunday, August 17: MS Tugboat Parade & Muster
MS Shoreside Festival
at Portland Ocean Terminal on Casco Bay

Join us as we kick off a waterfront weekend beginning Thursday, August 14th through Sunday, August 17. On Thursday evening, August 14th, a benefit auction featuring auctioneer Tom Saturley will start the weekend celebration. Silent and live auctions will feature hundreds of unique items donated by local artists and merchants. The title sponsor for the MS Harborfest Auction is Bangor Savings Bank.

On Friday evening, August 15th, the Sponsor and Skippers reception for the sailboat Regatta, sponsored again this year by Mercedez Benz of Greenwich, will take place at Handy Boat in Falmouth where boaters and sponsors come together to enjoy the evening's festivities while gearing up for the weekend's events.

On Saturday, August 16th, the annual MS Harborfest Parade of Sail will take place with more than 130 boats sailing through Portland Harbor. Following the parade boats will compete for position at the starting line off Fort Gorges in Casco Bay for the annual sailboat race.

Also on Saturday, August 16th, the annual MS Harborfest Powerboat Poker Run will take place on Casco Bay. The Poker Run is not a speed race and entry is open to boats of all sizes. Registration is at Portland's Dimillo's Floating Restaurant, from 7:00 a.m. to 10:00 a.m. Boats cruise to card-station boats along the course in Casco Bay to pick up a playing card; the highest poker hand wins valuable prizes upon their return to DiMillo's where a barbeque and awards party is held.

On Sunday, August 17th, it's fun for the entire family at the annual MS Harborfest Tugboat Parade and Muster and MS Harborfest Shoreside Festival, which takes place on the Maine State Pier. The festivities are open to all so come on down and watch the best of the area's working tugboats as they rally and race off to Portland's Eastern Prom. The tugboats will be berthed at the Maine State Pier on Sunday morning, where shoreside exhibitions, competitions, food and entertainment will provide a spectacular day of fun. The MS Harborfest Tugboat Muster and Shoreside Festival is sponsored by Bangor Savings Bank.

Money raised through the MS Harborfest helps fund research and supports local programs. For additional information about MS or the MS Harborfest weekend contact the Maine Chapter of the National MS Society at 207-781-7960, or visit our web site at www.msmaine.org.

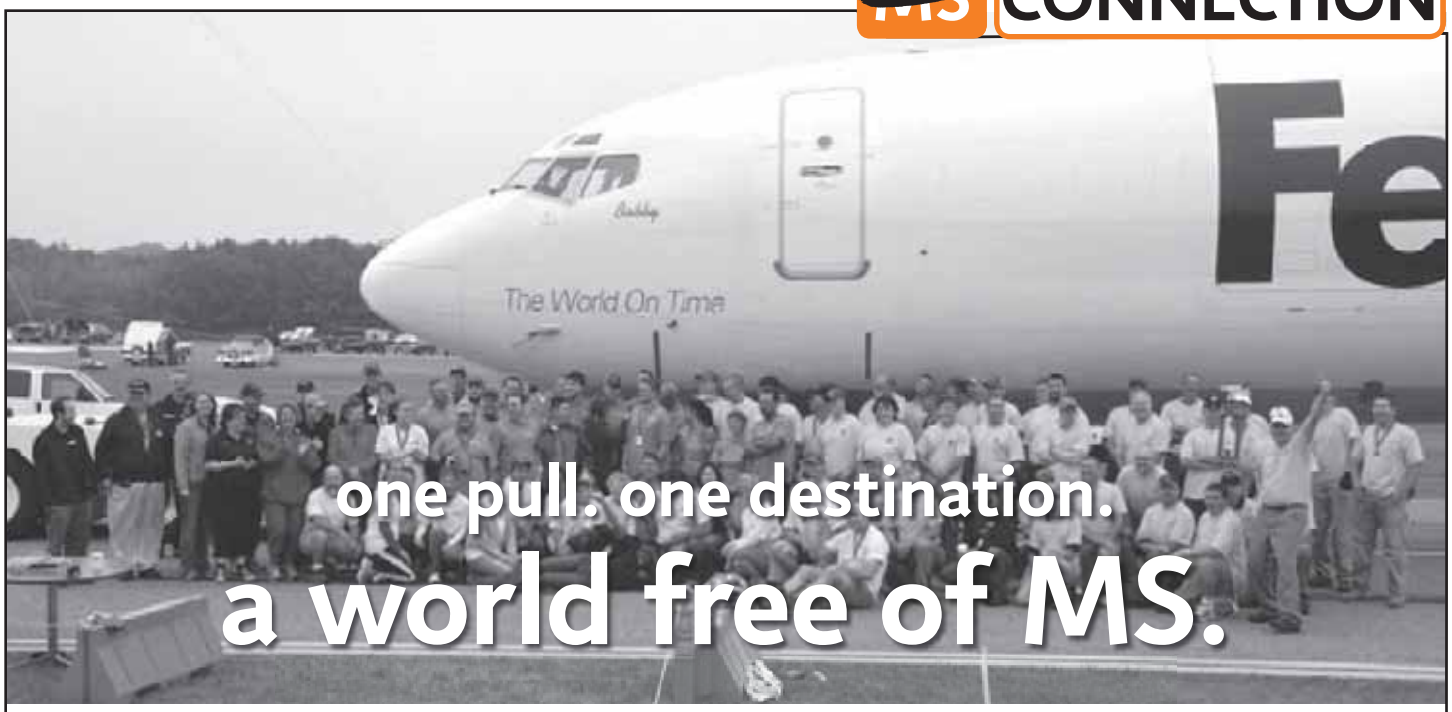
The walk MS: Manpower Maine Walk 2008 raised over $405,000!

As the skies cleared, 3,200 walkers took to the streets and not only raised funds, but raised awareness about multiple sclerosis. Congratulations and thank you to the walkers, committee members and volunteers who helped make the 2008 walk MS a huge success!

Our sincere thanks go out to Manpower, the title sponsor of the walk MS for eight consecutive years, and our other statewide sponsors: Woodard & Curran, Poland Springs, MEMIC, Lamey Wellehan, Homestead Building Supply, CES Inc, Time Warner Cable, Down East Magazine, 94.9 FM WHOM, WLBZ, G.M. Pollack & Sons, Tim Horton and Subway. We also are very appreciative of the support each walk site receives from local sponsors, vendors and businesses by donating supplies and services which make the day of the walk a memorable experience. Your support is so important to having a successful walk. Thank you for moving us closer to a world free of MS!

Mark your calendar: 2009 Walk MS: April 25th
Register at www.MSmaine.org or 1-800-526-8890

JOIN THE MOVEMENT



MS Plane Pull: September 20, 2008

The MS Plane Pull will be held on **Saturday, September 20, 2008**, at the Portland Jetport. Teams of 20 will take turns pulling a FedEx 727 aircraft down the runway, competing to win prizes and raising money for the Maine Chapter of the National MS Society. The minimum team pledge is **$1,000** and all proceeds go to benefit the Maine Chapter of the National MS Society. Join the movement for this unique and incredible team building experience and help us move closer to creating a world free of MS!

Register as a team with co-workers, friends or family!
Play **tug-of-war** with an aircraft!
Bring **family & friends** along for a full day of fun!
Challenges:
Teams will compete in three challenges:
◊ **Fastest Pull**
◊ **Team Spirit**

Everyone receives a **medal** and winning teams receive a **plaque**

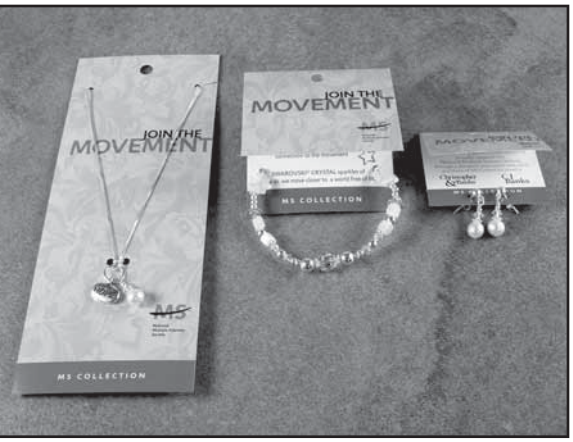
To register call Mufalo Chitam: 207-781-7960 or mail: Mufalo.Chitam@nmss.org

JOIN THE MOVEMENT

MS Awareness bling

As MS Awareness week 2008 kicked off this March, Christopher & Banks launched their second limited-edition MS Jewelry line.

This year, the MS Collection includes pearl and crystal earrings ($14), a lavaliere-style quartz and pewter necklace ($20), and an elasticized pearl, quartz, and crystal bracelet ($24). Half of the proceeds will benefit the National MS Society.



Last year, Christopher & Banks raised more than $120,000 through MS Jewelry sales.

The collection is available in nearly 800 Christopher & Banks and CJ Banks stores nationwide, as well as on their Web site. Visit **christopherandbanks.com** and type "MS" in the search field.

MS Research Loofa Dog

Got a pooch who loves to play? Dogs and dog-lovers alike will love this exclusive, orange plush toy with its super-wide grin and MS Awareness message. Loofa Dog's long (12") tubular shape makes him easy to pick up and carry around—and he squeaks when squeezed (or chewed).

Visit **carealotpets.com** and type "MS Loofa Dog" in the search field. Care-A-Lot will donate the profits to the Society's Promise: 2010 Campaign.

About Promise: 2010

This is a nationwide Society effort to raise $30 million for MS research by the year 2010. Read more about the promise at **nationalmssociety.org/Promise2010**.

Developing young minds

Developers Diversified Realty, one of the Society's valued corporate partners, announced that it will fund 10 of the top scholars in the Society's Scholarship program over the next four years, for a total of $120,000.

Over the last three years, Developers Diversified has supported the movement to end MS with an art auction, through Walk MS teams, and by placing MS Awareness posters and other signage in their malls and shopping centers throughout the country during MS Awareness Week.

The National MS Society Scholarship Program

Applications for scholarships will be accepted between October 15, 2008, and January 15, 2009. They will be available then on our national Web site, or call us. For more information, visit **nationalmssociety.org/Scholarship**.

Self-Help Group Listing

June-August

Self-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, or call 1-800-344-4867 (Select Option 1) for more information about the following groups:

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

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.

HAVE YOU BEEN RECENTLY DIAGNOSED WITH MS?

Are you looking for information, support, and connection to others newly diagnosed? The Maine Chapter of the MS Society would like to start a Newly Diagnosed Group that meets at the Falmouth office. The group will meet once per month for six months and topics covered will include MS symptoms, medication, work issues, and family concerns. If you are interested please contact Traci Chenette at 1-800-344-4867 (press option 2) or e-mail Traci.Chenette@nmss.org.

REACH OUT TELEPHONE SUPPORT GROUP

A Reach Out Support Group is a different kind of support group, it "meets" once per month via conference call. You can call in from anywhere in Maine and connect with other people with MS. If you are interested in participating in a Reach Out Telephone Support Group please contact Traci Chenette at 1-800-344-4867 (press option 2) or e-mail Traci.Chenette@nmss.org.

MS Learn Online

MS Learn Online is the National Multiple Sclerosis Society's online education program. Each webcast features experts presenting on topics relevant to those affected by multiple sclerosis. MS Learn Online webcasts are typically about 10 minutes in length and offer a convenient way to educate people about MS from the comfort of their home. To access MS Learn Online, go to nationalmssociety.org/mslearnonline.

Upcoming MS Learn Online webcasts:

Date: July 17, 2008
Topic: Hold That Thought! Cognition and MS: Management Strategies

Date: August 7, 2008
Topic: The Evolution of Therapies and Information in MS and Disease Management Strategies with Jock Murray, MD, Director of Dalhousie MS Research Unit in Halifax, Nova Scotia

Date: August 21, 2008
Topic: Rehabilitation Counseling: Is It For Me?

Real Talk. Real Answers.

Living With MS in Your 20s and 30s

Real Talk. Real Answers is a webcast specifically for young adults living with MS. Topics covered include relationships, disclosure, dating, pregnancy, and living well with MS. Getting a diagnosis of MS in the prime of your life can be overwhelming. This webcast offers a candid, real, and frank discussion of some of the questions and concerns you may be having, and it is available when you want it right on your computer! Go to www.realtalkrealanswers.com.

Special Programs

Picnic in the Park – Cascade Park, Bangor

Date: July 30, 2009 Time: 11:00 a.m. – 1:00 p.m. Location: Cascade Park, Bangor

Come join us at Bangor's Cascade Park for a casual, social get-together for people with MS (friends and family, too!). Bring your own lunch; we will bring cold drinks! We will be sitting at the picnic tables under the trees near the fountain.

Online Programs

MS Self Help Groups

A Self help Group provides an opportunity to share information, receive and provide support, and just talk to other people who know what it is like to live with MS. Friends and family members are always welcome. There are Self Help Groups in Augusta, Belfast, Brunswick, Caribou, Ellsworth, Falmouth, Lewiston, Rockland, Millinocket, South Portland, Sanford, and York.

MS Buddies/Peer Support Program

The MS Buddies program links participants with volunteer "Buddies" to provide consistent, short-term, one-on-one support. A 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.

Adaptive Aquatics-Southern Maine

Exercising in water can have many benefits for people with MS. Richard's Pool in Cape Elizabeth offers a class taught by staff trained in adapting exercise for all levels of ability. There are no classes this summer, but call to ask about the fall schedule 799-2868.

Adaptive Yoga

Date: Thursdays
Time: 10:30 am -11:30 am
Location: Brewer Auditorium/Parks and Recreation Department

Contact yoga instructor Bunny Barday, 989-5199, to register for this weekly yoga class. cost is $12/month for Brewer residents, $15/month for non-Brewer residents.

For more information about any of these programs, call 1-800-344-4867, and select option 1.

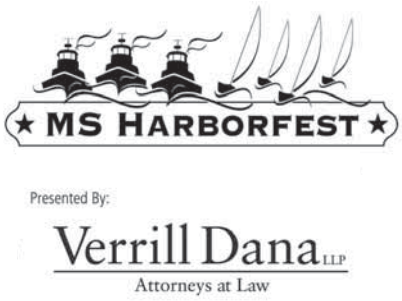
Are You Worried About the Cost of Heating Your Home This Winter?

The cost of fuel could make this winter a financial challenge for many Mainers. The Low Income Home Energy Assistance Program (LIHEAP) may be able to help with the high cost of heating your home this winter. LIHEAP can help income-eligible households with the cost of oil, gas, electric, coal, kerosene or wood, needed to fuel your home. To apply, contact your nearest Community Action Program (often referred to as CAPs) and ask when they will start to accept LIHEAP applications. You may need to make an appointment, and this is likley to be a busy winter for LIHEAP. If you need help to find the CAP that served your county, just call us at 1-800-FIGHT-MS (1-800-344-4867) and ask for the CAP in your area. Community Action Agencies can also help with weatherization strategies that can make your home more energy efficient and cheaper to heat.

Save the Date!

Bike MS
August 2nd and 3rd, 2008

27th annual MS Harborfest weekend
August 14th and 17th, 2008



MS Plane Pull
September 20th, 2008

Walk MS
April 25th, 2009

National
Multiple Sclerosis
Society
Maine Chapter

National Multiple Sclerosis Society
Maine Chapter
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Faimouth, ME 04105
www.msmaine.org

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