



# MS Connection

July - September, 2003

Maine Chapter

## Beth Powers Is New Chapter President

Please join us in welcoming Beth Powers as the new Chapter President for the Maine Chapter, National Multiple Sclerosis Society.

Beth brings a wealth of fund raising and communications experience to the MS Society, most recently as Director of Development and Community Relations at the Spurwink School. She serves on the Board of Directors of the Learning Disabilities



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See "MS In Motion" or go to [www.msmaine.org](http://www.msmaine.org) for event details.

## June in October? YES... At Our Annual Meeting!

Look for June Halper once again on **October 4<sup>th</sup> at MS Insights: Annual Meeting & Education Day**. When we realized that she would be speaking to *nurses* in April, we wanted her back to share her expertise about MS care with *all* our clients.

Keynote speaker June Halper is a certified adult nurse practitioner who has specialized in MS since 1978. She was a founder of the Gimbel MS Center in Teaneck, NJ and is the Executive Direc-

tor of the Consortium of Multiple Sclerosis Centers, the largest organization of MS healthcare professionals in the world.



*Noreen Comeau, June Halper, and Lynn Howard.*

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**Our mission is to end the  
devastating effects  
of multiple sclerosis.**

**How To Reach Us:**

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National MS Society  
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Web Site: [www.msmaine.org](http://www.msmaine.org)  
E-mail: [info@msmaine.org](mailto:info@msmaine.org)**

**To reach our Outreach Office  
(serving people in Aroostook,  
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**Maine Chapter Outreach  
Office, NMSS  
735 Main Road North  
Hampden, Maine 04444  
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[ksawyer@adelphia.net](mailto:ksawyer@adelphia.net)**

**2003 Call To Action**

Thanks to significant advances in research, the FDA has approved several treatments that may alter the underlying disease course in multiple sclerosis, and early treatment is critically important. People with MS should consult their doctors about using one of the FDA-approved medications and other effective treatments for the symptoms of MS. If you or someone you know has MS, contact the National MS Society at [www.nationalmssociety.org](http://www.nationalmssociety.org) or 1-800-FIGHT-MS.

## Beth Powers, New Chapter President

*Cont. from pg. 1*

Association and Children's Theatre of Maine. Beth graduated from the University of New York at Albany, and is a graduate student at the University of Southern Maine in the School of Business. Beth holds advanced certifications in rehabilitation counseling and teaching English as a Second Language. She is an avid landscape painter; and is a member of several arts organizations.

Beth's first love is helping people and communicating, whether she is traveling, making a presentation or painting a picture. Beth spent over five years in South America and Japan, teaching English as a Second Language. While there she volunteered in several hospitals and care centers. When she returned to the United States, she decided to move more directly into counseling and helping people with disabilities. She became a rehabilitation councilor and an activities therapist, and her experience led her into non-profit management.

Beth's love of Maine and the people is palpable. She is enthusiastic when talking about the connections that we are able to make in our state. "People in Maine want to talk and get to know you. Everywhere I go, I meet people I remember vividly with a story they have told me or something we have done together. Those are the connections we keep." says Beth.

With a strong desire to keep helping people, she joins the Maine Chapter of

the MS Society with enthusiasm. "When I met the board, the staff and some of the volunteers, I knew I was 'home'. I look forward to continuing the fine work of the chapter staff and volunteers, raising funds to support research and programming, increasing awareness about living with a disability in Maine, and providing quality resources, programs and services to people affected by MS, their families, friends, and healthcare practitioners", said Beth.

For more information about MS or the MS Society, call 1-800-FIGHT-MS or log onto [www.msmaine.org](http://www.msmaine.org).

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## Nancy Schatz Honored

Nancy Schatz was recently honored as a volunteer extraordinaire by the Holocaust Human Rights Center of Maine for her years of service to the center's educational programs.

An Augusta resident, Nancy, 59, has volunteered her services to a number of organizations including the Maine Chapter, National Multiple Sclerosis Society, the Arthritis Foundation and the Holocaust Human Rights Center of Maine. She has been volunteering since before the birth of her first child.

Nancy has managed the MS Society's Augusta Equipment Loan Closet.

The award was given at the Center's 18<sup>th</sup> annual meeting in South Portland.

# Maine Targets Landmark Reforms

Gov. John Baldacci has introduced landmark health care reform legislation that creates the framework for providing accessible, affordable and quality health insurance to thousands of Maine's uninsured citizens, self-employed individuals and small businesses (under 50 employees).

The Maine Chapter has gone on record in support of LD 1611, with the position that it provides the framework for meaningful health care reform, addressing access, quality and cost. The Dirigo Health Plan functions as an insurer. It covers physician visits, hospital costs and prescription drugs. Co-pays may be involved depending upon a person's income level.

Under the plan, individuals and families that fall below 300 percent of the federal poverty income guidelines (\$26,940 for an individual, \$45,780 for a family of three, or \$55,200 for a family of four) will be subsidized. For every individual eligible for Medicaid, the state will be able to draw \$1 for every \$2 expended from the federal government. Additionally, individuals, self-employed persons and small businesses would have the option of buying into the plan. Unlike Medicaid, Dirigo Health will reimburse health care providers at market rates negotiated by private health insurers.

At the time of our newsletter deadline, members of the Special Health Care Reform Committee had recommended LD 1611 and 1612 ought to pass, and the Legislature was due to

## Focus On Advocacy

vote on the proposal. The Governor is has been pressing for the plan to pass this year, saying something needs to be done now.

Access is another issue that the Maine Chapter champions. Earlier this year, our Advocacy Steering Committee voted to partner with Alpha One in the statewide ADA Coalition. Presently, the coalition is studying projects that will benefit people with disabilities. The next meeting is set for Monday, July 14 at 5:30 pm at the MS Society, 77 Preble St., Portland.

While the Maine Chapter advocates on behalf of issues that will benefit people in Maine with MS, we encourage you to participate, as well. We are always seeking people to be part of our Action Alert Team, individuals who will contact their state legislators or Congressional Delegation when requested. We send e-mail notices with talking points you can use when discussing a particular issue. All we ask is that you make the calls. It is amazing that as few as five calls to a state representative or senator can impact their decisions. Numbers can and do make a difference, and we need those numbers to help you.

For more details about Action Alert, or our advocacy program, contact BJ Bangs, at 761-5815, 1-800-639-1330 or [bjbangs@msmaine.org](mailto:bjbangs@msmaine.org).

## Erin Fotter: A Personal Perspective

*Erin Fotter, 21, is the daughter of Linda and Stephen Fotter of Benton, Maine. She recently graduated from Wilson College. In December of 2002, two members of the MS Society staff attended a wonderful concert of holiday music that her family gave to benefit the Maine Chapter, NMSS. After meeting this remarkable young woman, we asked Erin if she would write something about herself for our newsletter. Here are Erin's words.*



I realize that as I grow older, I am better able to understand how much of a miracle my mother is. My mom, Linda, was diagnosed with multiple sclerosis in December, 1991. I don't remember much about the actual day, but I do remember spending Christmas in the hospital with the nurses and singing carols to other unfortunate patients who had to spend the holiday there. My mom had been working as a bookkeeper at a local lumber company; however, the diagnosis would change all of that. She was forced to stay at home during the day and was not allowed to drive at night because of the effects of the disease. I would later come to appreciate the fact that she was always there when I got home from school.

My mother battles fatigue daily. She also suffers from constant numbness in her right side, and at times of severe attacks, her vision is blurred. She has a slight limp in her right side when she

walks, which is caused by the numbness. Her concentration requires twice as much energy as a normal person, which causes fatigue. It takes her twice as long to adapt to new surroundings and she easily falls if the floor is not even. If I take a step back and look at everything that has affected her because of this disease, it is overwhelming to see how she has come so far and not relapsed. My mother has been diagnosed for almost 12 years now and is still considered Relapsing-Remitting. She feels as though she has had the disease for twice as long, but it was never correctly diagnosed because of the lack of knowledge and technology.

Because of my mother's diagnosis, I have been motivated to pursue a career in finding a cure. I performed my senior thesis on understanding the cell involved with multiple sclerosis patients. The title was 'Characterization and Differentiation of the *Murine* Oligodendrocytic Cell Growth Lineage Utilizing Ultrastructural and Histochemical Techniques'. Through that, I learned many different techniques, which are performed daily in laboratory facilities. Because of my research, I have now landed an internship at Johns Hopkins Bayview Medical Campus as a research technician for two years. I will be working on mouse and human embryonic stem cells. The research is not directly associated with multiple sclerosis, however it gives me a better understanding of techniques and processes to use when I eventually

*Cont. on pg. 7*

## Developing A Green Thumb & ...

*"To nurture a garden is to feed not just the body, but the soul."*

Alfred Austin

Many people gain a great sense of satisfaction, independence and high self-esteem in caring for living plants. A garden can be a wonderful tool to help people recognize that they can continue an activity that is meaningful to them, regardless of their limitations.

Exercising your green thumb helps to burn calories, improve motor skills, and can be a wonderful outlet for stress and creativity. People of different ability levels are able to garden because they can do as little, or as much as they want, at their own pace. Simple tricks, like modifying garden styles and using innovative tools, are allowing more people to roll up their sleeves and get into the dirt.

Helpful hints to make gardening easier:

- ❑ Use equipment that is easy on the body. Buy lightweight tools with large handles. Mechanical seeders and seed tape eliminate the need to pick up tiny seeds. Garden shops, nurseries, gardening catalogs and websites sell specially adapted tools for easy grip.

- ❑ Wear an apron with large pockets to carry seeds and tools. Adapt tool pouches to hang from walkers, wheelchairs/scooters or flowerbeds.

- ❑ Design raised beds or window

boxes that you can easily reach without stretching or bending.

- ❑ Choose the size of the garden and types of plants to meet your needs. Consider the plant's height, the amount of attention it requires, and its lifespan. For example, vine plants (peas, beans, etc.) can grow on a trellis and are then easier to harvest. Plants that need less water may be easier to maintain.

- ❑ Make your work area accessible for you. Build handrails or handgrips if needed.

- ❑ Pace yourself. Have a cool resting place nearby and be careful that you don't get overheated.

For more tips on gardening, contact the University of Maine Extension Office at 1-800-287-0274 or log onto [www.umext.maine.edu](http://www.umext.maine.edu). Ask them about their master gardeners who are ready to help you. The season is now!

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### Lewiston-Auburn Support Group Hosts Annual Barbecue

The Lewiston-Auburn Support Group (both caregivers and the regular support group) is hosting an annual barbecue, get-together on Sept. 7 at Range Ponds State Park. Reservations are needed by Aug. 1. Bring your own food for the grill, a sidedish, and soft drinks or water. For more information, contact Lowell Iller, 783-5807, or Ronald Pomerleau, 783-1863.

## Lean Online: 'Vision and MS'

'*Vision and MS: What We Need to Know*' will be the focus of the next MS Learn Online, the National Multiple Sclerosis Society's quarterly Internet educational program. The event will be offered live Thursday, Sept. 18 at 8:30 pm.

Elliot Frohman, MD, Ph.D., associate professor, neurology and ophthalmology, and Director of the Multiple Sclerosis Program at the University of Texas Southwestern Medical Center, Dallas, TX, will be the presenter.

MS Learn Online programs are presented quarterly for people with MS. They can be viewed live the day of the program or can be accessed anytime from the

archive on the NMSS website, [www.nationalmssociety.org](http://www.nationalmssociety.org). Select "Living With MS", then "Webcasts and Conferences". Free software to view and listen to these programs can be downloaded from the site's Technical Support section found in "Webcasts and Conferences".



**Disability Consulting Group** is the nation's leading consultant and full service reinsurance manager for group disability, life, AD&D & critical illness. DCG's staff of professionals possess in-depth product knowledge; an understanding of the dynamics and the competitiveness of the marketplace; and demonstrated expertise in organizational assessment, strategic planning, product development, contract filing and compliance, underwriting, pricing, claims management, and research and marketing.

*The Maine Chapter, National MS Society, thanks Pam Saunders and the Disability Consulting Group for their title sponsorship of the recent Women Against MS (WAMS) Leadership Luncheon.*

## Erin Fotter's Personal Perspective

*Cont. from pg. 5*

pursue a job that is directly associated with MS. Because of my mom and because of the talents God has given me, I am actively pursuing this type of research, and God is currently blessing me. I couldn't have done any of this without her, because she has been my foundation. She is my mother, my listening ear, my letter writer, my e-mail sender, my advice giver, but most importantly my best friend. I thank God that He has given me the appreciation of her as I've become older. I am truly blessed to have her for a mom. Thank you mom for being who you are.

## MS Research Advances Show Promise

**Complementary Therapy Explored** – A study by Dr. Barry Oken and colleagues (Oregon Health Sciences University, Portland, OR) compared a six-month regimen of **adaptive yoga or exercise** (stationary bicycle and home exercise) to a non-exercising control group in over 50 individuals with different forms of MS. The study found significant improvement in fatigue over the control group, but no impact on cognitive function.

**Aricept® Shows Potential** – Researchers are investigating whether Aricept, a drug shown to improve memory in Alzheimer's disease, can improve memory in MS. According to clinician and patient reports, 35 subjects taking Aricept showed significantly greater improvements on a

memory test than 34 subjects taking placebo. Larger studies are needed to confirm the safety and benefits of this medication.

**Nerve Tissue Repair in Mice with MS-Like Disease** – Researchers in Milan, Italy published landmark results of studies in which they successfully injected adult mouse neural stem cells to promote tissue repair and clinical recovery in mice with MS-like disease. These results represent an early but significant step forward in the effort to find a way to repair nerve tissue damage for people with MS. These results must be viewed with caution, given the differences between mice and humans. Further studies will be needed to address issues involved in studies that involve humans with MS.

### Upcoming Programs

- July 29 ----- Diagnosis MS: Getting Connected, for people newly diagnosed, Hampden.
- July 30 ----- Diagnosis MS: Getting Connected, for people newly diagnosed, Portland.
- Aug. 28 ---- An Evening with Dr. Patricia Coyle, Lewiston.
- Sept. 9 ----- Free MS Legal Clinic, Portland.
- Sept. 13 --- Free Physical Therapy Clinic, York.
- Sept. 17 --- Reach Out! Teleconference, for those unable to travel to support groups.
- Monthly**-----Kids Konnect, 4-5 pm, 3<sup>rd</sup> Thursday of the month, An interactive website for children ages 8-12 facilitated by Maine Chapter staff.
- Ongoing**-----Aquatics classes, Casco Bay YMCA, Freeport. Tuesdays & Thursdays, 4-4:45 pm.
- Save the Date:**  
**October 4! MS Insights: Annual Meeting & Education Day,**  
**9 am - 1:30 pm** Double Tree Hotel in Portland.

*First Maine Women Against MS (WAMS) Leadership Luncheon*

# WAMS Attracts 350 Guests, Raises \$30,000

Pictured below: Beth Powers, Chapter President, MS Society; Dr. Nancy Richert, NIH, Pam Saunders, Disability Consulting Group and JoAnn Roy, guest speaker.

JoAnn Roy,  
Dr. Nancy Richert  
& Chellie Pingree.



Debbie Cupo & friends.

Emcee WCSH-6 anchor Shannon Moss and former State Sen. Chellie Pingree who addressed Disability Rights in the Workplace.



Elizabeth McLellan, MS Society Board of Trustee, & friends.



MS Society Honorary Board Member Maddy Corson, above, and Susan Greenwood, former executive director MS Society, at right.



Jennifer Gillespie, MS Society volunteer with friends.



Amy Beckers, of the WAMS Planning Committee, with her husband Carl.

**Peer Support Groups: July - September 2003**

Peer support groups offer education about multiple sclerosis, emotional support, and can serve as an information and referral source.

**Augusta:** 1<sup>st</sup> and 3<sup>rd</sup> Thursday of the month, 5:30-7 pm. *Contact:* Debbie Hutchinson, Hutch303@aol.com, 582-5009.

**Bath/Brunswick:** 2<sup>nd</sup> Monday of the month, 7 pm. *No meetings July & August. Contact:* Nan Curtis, 666-8822.

**Bethel:** 1<sup>st</sup> Friday of the month, 1-2:30 pm. *Contact:* Gale Tout, gtout@megalink.net, 836-2900.

**Boothbay area:** New group forming soon! Contact Kelley at the Maine Chapter Office, 1-800-639-1330.

**Caribou:** Irregular meetings. *Contact:* Vicky Bolstridge, 473-7668.

**Ellsworth:** Last Thursday of the month, 7 pm. *Contact:* Helen Kazura, hkazura@acadia.net, 667-9460, or Rick Alexander, 374-3766, riktexan@acadia.net.

**Fort Kent:** 4<sup>th</sup> Tuesday of the month, 7 pm. *Contact:* Sandy Pelletier, 834-3155 x3218 or Brian Voisine, 834-3129.

**Freeport:** 2<sup>nd</sup> & 4<sup>th</sup> Wednesdays of the month, 10 am. *Contact:* Dan Morency, 865-4807; prefers e-mail, DMorency@gwi.net.

**Hampden:** 2<sup>nd</sup> Wednesday of the month, 6-7:30 pm. *Contact:* Claudia Fish, 234-2715, hitsongs@uninets.net.

**Hampden:** 1<sup>st</sup> and 3<sup>rd</sup> Monday of the month, 10:30 am-noon. *Contact:* Dick Wing, 947-5868, or Katherine Tsoulas, gypsysoul@adelphia.net, 990-0383.

**Houlton:** Irregular meetings. *Contact:* Kathy Estabrook, 532-0763, or Linda Cowen, 448-2437.

**Lewiston/Auburn:** 2<sup>nd</sup> Wednesday of the month, 6:30 pm. Caregivers group meets simultaneously. *No meetings July & August. Contact:* Marcia Humason Akers, 998-4944, or Noreen Comeau, 782-5522. See

info about the group's first annual barbecue on page 6.

**Madawaska:** 1<sup>st</sup> Monday of the month, 1-2 pm. *No meetings July & August. Contact:* Theresa LaGasse, 728-3349, LaPuss@gwi.net, or Cecile St. Jarre, guysj@nbnet.nb.ca, 728-7066.

**Madison:** 3<sup>rd</sup> Monday of the month, 3-4 pm. *No meetings July & August. Contact:* Audrey Carrigan, 696-3419, acarriagan@gwi.net, or Vicki Bolduc, 474-2930.

**Millinocket Area:** 1<sup>st</sup> Tuesday of the month, 6:30 pm. *Contact:* Chris Carlstrom, 723-4317, or Lori Fleming, 746-9457, kilby@webtv.net.

**Mountain Valley:** 1<sup>st</sup> Sunday of the month, 6-7 pm. *Contact:* Gene Casey, 369-9065.

**Piscataquis County:** New group starting soon. *Contact:* Maureen Doore, 564-8232.

**Pittsfield:** Meetings change monthly. *Contact:* Jan Moore, 487-0916 x207, rjj@gwi.net.

## Support Group Meetings July - September

*Cont. from pg. 10*

**Sanford:** 2<sup>nd</sup> Thursday of the month, 7 pm. *No meetings July & August.*  
*Contact:* Nancy Albin, 324-3907.

**South Portland:** 3<sup>rd</sup> Tuesday of the month, 5:30-7 pm. *Contact:* Ron DuPont, 741-2310.

**Togus:** 3<sup>rd</sup> Tuesday of the month, 11 am-noon.  
*Contact:* Nan Curtis, 623-8411 x5501.

**Waldo/Knox County:**  
*No meetings all summer.*  
Will reorganize in fall.  
*Contact:* Annette Spear, [jasajs@midcoast.com](mailto:jasajs@midcoast.com).

**Washington County:** If anyone is interested in leading or joining a group, contact: K Sawyer at the Maine Chapter Outreach Office, 1-800-273-4703.

**York:** 2<sup>nd</sup> Thursday month, 7-9 pm. *Contact:* Mary Jane Merrill, [dobbin3@earthlink.net](mailto:dobbin3@earthlink.net), 363-7767, or Katherine Tucker, 363-0525, [kvtucker@gwi.net](mailto:kvtucker@gwi.net).

## Other Ways to Give

### *Creating a Legacy for Tomorrow... If Only We Had Known . . .*

**T**he National Multiple Sclerosis Society recently received a surprise bequest of \$10,000 from the estate of a woman we had never thanked. Of course, we appreciated the gift immensely. It revealed a gracious and generous person - someone special. The gift will certainly help us accomplish our mission of ending the devastating effects of multiple sclerosis.

But we feel a bit cheated. We never had the opportunity to express our gratitude to her for such kindness. We were unable to let her know how much her gift would mean. If only we had known, we could have said, "Thank you."

We encourage our friends to let us know when they include the Society in their estate plans. Not only can we express our appreciation, but also we can make sure that they are kept up to date with all of the developments the Society makes toward a cure for MS.

The Society has established the "Pillars of Society" which recognizes those who have included the Society in their estate plans. Members automatically receive a certificate signed by General Mike Dugan, President and CEO, special updates throughout the year, and an invitation to attend a special Leadership Dinner at our annual National Conference.

If you've named the Society in your estate plans, please contact Beth Powers, Chapter President, at **1-800-639-1330** or e-mail [bpowers@msmaine.org](mailto:bpowers@msmaine.org) or [giftplanning@nmss.org](mailto:giftplanning@nmss.org). If not, perhaps you will let us send you a free but valuable guide, "Creating a Legacy Through Your Will," about gift and estate planning. It is worth reading whether or not you choose to make a future gift to the National Multiple Sclerosis Society.



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## ***Special Events News***

Join cyclists from throughout Maine and register for the **MS 150 Bike to the Breakwater**, Aug. 2-3 at Saint Joseph's College, Standish. To date, 329 cyclists have registered.

The **MS Regatta Harborfest** is set for Aug. 15-17. See '*MS In Motion*' or log onto [www.msmaine.org](http://www.msmaine.org) for more details.

The **2003 Manpower MS Walk** was the best ever. Over 4,200 walkers raised \$500,000. Thanks to our many participants, volunteers and sponsors. Log onto [www.msmaine.org](http://www.msmaine.org) for more details.