

msconnection

Utah State Chapter

The National MS Society...One thing people with MS can count on.

**MS 150
Bike Tour
Brochure
Inside!**

Women Against MS Champagne Luncheon Reaches New Heights

The Utah State Chapter held the fifth annual Women Against MS Champagne Luncheon on Saturday, February 28 at the Little America Hotel to raise money for MS research and programs. During the luncheon, over 600 attendees learned about multiple sclerosis and enjoyed a spring fashion show presented by local clothing boutique, Great Garb. And it is because of a group of dedicated committee members and table captains that the Luncheon raised a record-breaking \$60,000.

This year, attendees enjoyed messages of hope from speakers who know what living with MS is really like. Cheryl Chatman, an inspirational speaker from the North Florida Chapter, encouraged attendees to live their dreams by actively fighting MS. Dr. Robert Fujinami, a neurologist at the University of Utah, gave an informative update on the latest MS

research findings. Jeannie Souvall Paxten, a native of Salt Lake City, explained how she finds hope through flexibility, faith, friends, family and fun. Each speaker sent a special message that proved that we can all play a part in the fight against MS.



Dr. Robert Fujinami gives a research update

To conclude the afternoon, Great Garb presented an incredible fashion show highlighting Spring 2004 fashions from designers like Theory, Leona Edmiston, and Isabella De Pedro.

Mark you calendars for next year's Champagne Luncheon, which will be held Saturday, February 26, 2005 at the Little America Hotel.

A Message of Thanks to Those Who Made WAMS a Success

The Utah State Chapter would like to thank the dedicated committee who teamed up to coordinate WAMS.

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The National MS Society is dedicated to ending the devastating effects of MS.

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CHAPTER NEWS

■ Women Against MS — *continued from page 1*

Philip McCarthy, Chair; Betsy Hunt, Co-chair; Ann Bagley; Debbie Don; Kelli Fratto; Anne Harte; Diane Henry; Hope Hooton; Maybell McCann; Melisa Mitchell; and Wendy Park worked very hard to ensure that WAMS was a terrific success.

This year's event had outstanding support from the McCarthy Family, ABC 4, Berlex Laboratories, Biogen Idec, Foothill Family Practice, Great Garb, Little America Hotel, McCune Mansion, Pfizer/Serono, Teva Neurosciences, Inc., The Zenith, Zions Park City Bank, IC Group, and Kelli & Lynn Fratto.

Dream to Discover The Cure: A Daughter's Story

By Crystal Coleman

I have always wanted to be a model or an actress. Just being in the spotlight always got me going. When I was little I would dance and sing around the house, hoping that one day I would get a chance in the spotlight. Then about five years ago, someone very close to me was diagnosed with multiple sclerosis — it was my stepfather.

This was a life-altering change for my family, including me. I had to start to do things around the house I usually did not do. When this first happened, I wasn't happy and would be selfish and not want to do it, until I saw my stepfather fall down the stairs because he had no feeling in his right leg. I slowly began to notice all the effects that MS was having on him.

His strength would come and go, and he wouldn't even be able to pick up something as simple as a fork, for it was too heavy for him to handle. He would also get really stubborn and try to pick up things on his own, which caused him to become even weaker.

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CHAPTER NEWS

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This is when some occasional fights would occur. I would tell him to let me help out and he would say "no." I then began to yell and tell him to stop trying to do everything himself and that he just needs to relax and let people help him for once. These fights continued for the next couple of years, and I still held onto my dream of one day becoming a model.

As I went through high school I noticed myself becoming very interested in the sciences, especially anatomy and biology. I also got involved in the National MS Society by volunteering for the annual MS Walk and the MS 150 Bike Tour. Through the Society, I met people who were affected by MS in very different ways.

These experiences continue to give me the drive to help people with this disease and give back to the community. I now am studying to become a nurse at Westminster College, hoping to expand my horizon with all the different options that nursing has to offer. It is now my dream to help find a cure for MS.

Thank You Coleman Family

The Utah State Chapter would like to thank Cindy Coleman and John Ahmuty for their support and generosity. For several years, Cindy contributed to the success of the chapter by serving on several committees and on the board of directors. John supported the chapter by serving on the MS Walk committee and by volunteering. Both were instrumental in securing valuable sponsorship for the MS 150 Bike Tour, the MS Walk, the Dinner of Champions, and the Women Against MS Champagne Luncheon. We wish them the best of luck in Los Angeles.



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RESEARCH

Exercise And Multiple Sclerosis

By Andrea T. White, Ph.D.

Increasing evidence supports that exercise improves many aspects of health; however, most Americans (60%) do not participate in regular physical activity. People with MS face even more barriers to activity. Many of the exercise challenges individuals with MS face can be overcome by obtaining a realistic and adaptable exercise plan.

While many patients with MS can benefit from exercise, the type and amount of exercise must be individualized by taking into account their fitness, expectations, interests, MS symptoms, and functional abilities. Daily fluctuations in fatigue and energy can make planning physical activity difficult. It is important not to ignore fatigue or other symptoms that may interfere with physical activity.

The solution is to adjust physical activities to fit the day's functional and energy levels, rather than abandon physical activity all together. Exercise intensity should be monitored using effort as the indicator. For cardiovascular health, "moderate" aerobic activity is recommended. The absolute exercise intensity that feels "moderate" to an individual depends on fitness and functional levels. The key is to adjust exercise intensity and duration as MS symptoms fluctuate. One day "moderate" might mean a brisk walk; on another day "moderate" could mean a walk at a much slower pace or for a shorter distance. For aerobic exercise, previously sedentary people should start slowly (10 minutes, 3 times per week) and gradually increase duration (up to 30 minutes, 3-5 times per week for general health benefits).

There are many safe and effective modes of exercise that can be successfully used to improve health-related fitness, as well as flexibility, balance, and coordination. A combined arm-and-leg ergometer (such as the Schwinn Airdyne) is an excellent training mode for people with

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■ Exercise & MS

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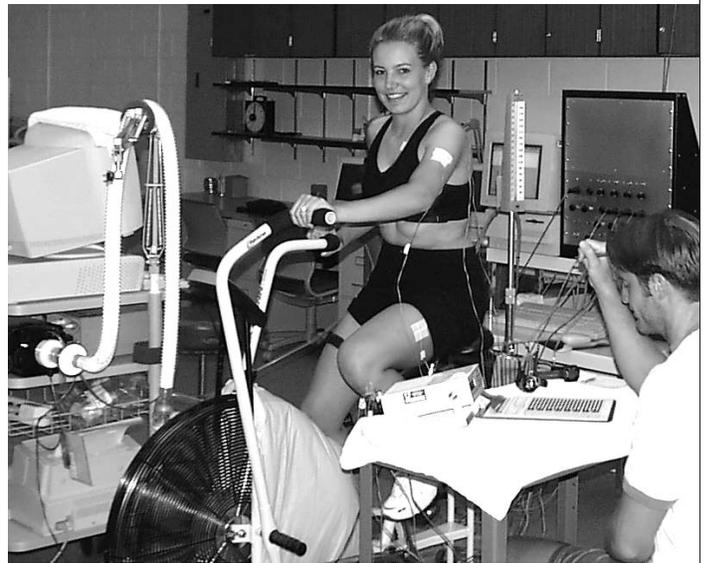
MS, because effort can be transferred from weak to stronger extremities, and work is dispersed over a large muscle mass. This type of cycle also provides support for body weight and a cooling effect during exercise through air resistance. Other "ergometers" such as rowing machines, elliptical trainers, and treadmills can also be useful.

Water exercise is also beneficial for people with MS because body weight is partially supported, making overheating less likely. Specific balance and coordination exercises can be performed with the support of water with little risk of injury when balance is lost.

People with weakness or ataxia can perform exercises in the water that might be too difficult on land. For example, gait and balance can be challenged by walking in different directions in waist or chest-deep water. Benefits of exercising in water include improved flexibility, posture, muscle tone, and coordination. In a normally heated pool, physical activity will not result in overheating.

More people are participating in activities like yoga and Tai Chi. In many cases, these activities can be adapted to limitations that people with MS may have. The meditative aspect of these forms of exercise can be excellent for reducing stress, achieving "balance", and focusing on the positive aspects of life.

There have not been many studies on the effects of strength training in people who have MS. However, strength training programs for populations with profound



weakness and muscular or joint impairments have been safely implemented with positive results. Appropriate multi-joint exercises to strengthen large muscle groups should be helpful in increasing muscle strength. Moderate resistance is preferable to heavy weights, and care should be taken to avoid severe fatigue. Improved muscular strength and endurance may be useful in maintaining or increasing balance, coordination, and functional status.

Once an exercise program is prescribed, the challenge of how to stick with it begins, a challenge that many healthy people find difficult. For some individuals, mobility and transportation are constraints. Dr. Petajan and colleagues at the University of Utah noted that the socialization and support received by people with MS who exercised as a group may have helped them stick with the program. Programs that include these kinds of motivational and supportive aspects are already becoming available. It is important to identify your own barriers and then search for solutions that will make

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■ Exercise & MS — continued from page 5

it easiest to regularly perform activities.

Many types of exercise can be performed by individuals with MS, and even a little bit of activity is better for health than choosing to be inactive. Guidance for designing an appropriate exercise program is available. Some communities have ongoing exercise and/or rehabilitation programs sponsored by MS organizations.

Increasingly, fitness leaders at health clubs have experience prescribing exercise to populations with specific needs. It may require a bit of research to locate a program

or facility that works, but it is well worth the effort. Choosing appropriate environmental conditions (safe, accessible), being able to modify exercise intensity and duration, and selection of an appropriate mode of exercise can safely maximize the benefits of exercise.

Current research supports including exercise as a part of overall health management for people with MS, and indicates that exercise can have an important impact by improving health and quality of life.

A CD that contains Dr. Andrea White's teleconference about "Exercise & MS" can be checked out from the Lending Library. Call 493-0113 for details.

Possible Link Between Vitamin D and Reduced Risk of MS Reported

A new study in nurses suggests that those with higher vitamin D intake may have had a reduced risk of developing multiple sclerosis. Kassandra Munger, and colleagues (Harvard School of Public Health, University of California at Irvine) report their findings in the January 13, 2004 issue of *Neurology*.



risk of developing MS than women who did not take vitamin D supplements.

This study adds new information to ongoing research focused on a possible role for vitamin D in reducing the risk of developing MS. There is no information in this study to determine whether vitamin D affects the course of MS once

it has begun. Further research is necessary to clarify these findings.

The study included 187,563 women, including 173 with probable or definite MS, enrolled in the Nurses' Health Study, which regularly surveys female registered nurses. Women whose intake of vitamin D were greater than or equal to about 400 IU/day from supplements and food, or from supplements alone, had a 40% lower

The U.S. government-issued "Adequate Intake" level of daily vitamin D for adults is 5-15 micrograms or 200-600 International Units. Excessive intake of supplemental vitamin D can have serious, toxic effects on the body.

MS Clinical Trials Update

The Clinical Trials feature of the National MS Society's Web site has been recently updated. Following is a summary of the articles and Web site address. You may also access the information through the Web site home page at: [nationalmssociety.org](http://www.nationalmssociety.org) - click on "Research" and "Clinical Trials".

- The list of "*Agents in Clinical Trial for MS*". This document lists more than 160 ongoing, planned, or recently completed studies of agents under study for MS. <http://www.nationalmssociety.org/pdf/research/agents.pdf>
- An expanded version for health care professionals contains extensive information on possible mechanisms of action for each agent, as well as study

results, if these are available. <http://www.nationalmssociety.org/pdf/research/clinicaltrials.pdf>

- "Trials Recruiting Patients". This section contains information about trials - indexed by state - that are recruiting people with MS. Studies are currently listed in 29 states, as well as several international sites. <http://www.nationalmssociety.org/Research-trialsrecruiting.asp>
- "Clinical Trials in MS - Getting Involved, Getting Results". This spotlight highlights the latest news related to clinical trials, studies funded by the National MS Society, and the profile of Ruth Ann Marrie, MD, a Society-funded Sylvia Lawry Physician Fellow, who is being trained to conduct clinical trials. [://www.nationalmssociety.org/spotlight-clinicaltrials.asp](http://www.nationalmssociety.org/spotlight-clinicaltrials.asp)

Participants Wanted For Research Study

The Multiple Autoimmune Disease Genetics Consortium (MADGC) is a group of genetic researchers who have joined efforts to identify and understand the genes that autoimmune diseases have in common. If at least two members of your family are affected with different autoimmune diseases from the list below, your family may qualify to participate in this important research study.

- ✓ Multiple Sclerosis
- ✓ Rheumatoid Arthritis
- ✓ Juvenile Rheumatoid Arthritis
- ✓ Systemic Lupus
- ✓ Type I Diabetes
- ✓ Ulcerative Colitis or Crohn's Disease

- ✓ Autoimmune Thyroid Disease
- ✓ Sjogren's Syndrome
- ✓ Psoriasis

Participation includes a brief telephone interview and providing a blood sample, which can be drawn at your local clinic or MD's office.

To learn more about this NIH funded study, visit www.madgc.org or call toll-free to either of these consortium members:

EAST: North Shore University Hospital, Manhasset, NY ■ 1-877-698-9467

WEST: University of Minnesota Minneapolis, MN ■ 1-888-226-8636

Buy a Bicycle or a Sneaker for \$1 at Harmons

Once again, Harmons, your neighborhood grocer, is making it possible for its customers to give to the National MS Society through the sale of MS Walk and MS 150 Bike Tour icons.

The MS Walk sneaker icons will be sold in late May and the MS 150 Bike Tour Bicycle icons will be sold in early June. They can be purchased for \$1 each at all Harmons locations.



Harmons, the title sponsor for both events, is one of the Utah State Chapter's biggest supporters. Last year, the local grocery store chain gave the chapter over \$35,000. Through the support of Harmons and other sponsors, fundraisers, and private donors, the chapter can continue to fund MS research and offer quality programs to Utah families affected by MS.

Stretching Tips to Get You in Shape for the MS 150 Bike Tour

The snow is melting and the road anxiously awaits your return. It is time to start training for Utah's MS 150 Bike Tour!

The American Physical Therapy Association provided this quick reference sheet to help make your riding experience more comfortable and enjoyable. The following stretches are commonly overlooked by cyclists. They are designed to keep your muscles flexible and to help improve performance. Perform each stretch 2-3 times, and hold with light to moderate pressure for 15-30 seconds. Be sure to avoid aggressive stretching or bouncing. This information is not intended as a substitute for seeing a physical therapist or other health care professional.

HAMSTRING STRETCH

TIPS : While sitting on the floor with your back held straight, gently lean forward. You should feel a mild stretch at the backs of your thighs.

HIP FLEXOR STRETCH

TIPS: While kneeling on your left knee, shift hips forward. You should feel a mild stretch at the front of your left hip and thigh. Repeat on the opposite side.

IT BAND STRETCH

TIPS : While leaning against the wall, and your left leg crossed in front of the right, shift your hips toward the wall. You should feel a mild stretch on the side of your right hip. Repeat on the opposite side.

We look forward to having you join us as we "Roll over MS" June 26 & 27.

Coach Urban Meyer invites you....

Join Coach Urban Meyer and friends as we **TAKE A SWING AT MS** at the 3rd Annual MS Celebrity Golf Classic. This year the Classic will be held Friday, June 4 at Murray Parkway Golf Course. Coach Meyer will bring Ute's football and basketball players (old and new), and other players like Greg Ostertag from the Utah Jazz, Derrek Parra of Olympic fame, Coach Jeff Judkins from BYU and many more.

Each foursome gets matched with a local "celebrity," and numbers are limited



to keep up speed of play. Join the ranks of quality corporate sponsors such as Workers Compensation Fund, Okland Construction, CB Richard Ellis and more. Hole sponsorships are still available (take "ownership" of a hole, and enter a foursome for \$1,000), but anyone can sign up and **TAKE A SWING AT MS!** then join us at the dinner party to follow. Get more information or sign up at fightmsutah.org, or call us at 1-800-FIGHT-MS.

Put the FUN back in FUNdraising!

Here at the Utah State Chapter, we don't take anything more seriously than raising funds to fight the battle against MS. But we do know that you can have a little fun while you are at it, and enjoy great fundraising success!

Our Web site (www.fightmsutah.org) now has a sample Fundraising Kit (with instructions) to download and help you with your fundraising goal for the MS Walk or MS 150 Bike Tour.

Research has proven that a mail campaign is one of the most effective methods of raising funds for our special events, and we want to make it as easy as possible for you! We have included a sample written letter to personalize and send, some sample MS 150 Bike Tour flyers that were very successful to give you

creative ideas (for an individual or corporate team), a contribution batch form (to submit pledges as you get them, instead of waiting for the event) and even a contribution card to take credit card information for pledges. We suggest sending out 20 letters to start. Just go to www.fightmsutah.org, click on MS Walk or MS 150 Bike Tour, then Fundraising Tips for more information.

Another great tool on our Web site is the Personal Web Page, available under both MS Walk and MS Bike Tour headings. Any registered participant can simply click on "My Account," log in with username and password, then click on "Create/Edit Personal Web Page." The instructions will walk you through creating your own team page or personal page, to be hosted

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"Walk All Over MS" at the 15th Annual MS Walk

2,000 Utahns Expected to Spend Time with Friends, Exercise, and Support a Worthy Cause

The National Multiple Sclerosis Society Utah State Chapter will hold the 15th Annual MS Walk, which will take place statewide on Saturday, April 17 beginning at 9:30 a.m. The popular fundraiser financially supports local multiple sclerosis programs and research, and is as easy as taking a morning stroll and gathering contributions from family, friends, and co-workers.

Walkers enjoy fully-supplied rest stops along the routes, which are wheelchair accessible and range from four to six miles in length. Routes are located in the following cities:

- **Salt Lake Area**
Utah Cultural Celebration Center
(1355 West 3100 South) **New Location**
- **Ogden**
Lorin Farr Park
(1650 S. Canyon Road)
- **Provo**
Exchange Park
(700 West 900 North)
- **Cedar City**
Providence Center
(Off South Interchange)
- **Vernal**
Colton Pavilion
(400 North 900 West)
- **St. George (March 27)**
Bloomington Park
(Off Man of War Road)

The MS Walk is designed to raise money for National MS Society-funded



research projects and local programs for those affected by the disease. This year, the chapter expects 2,000 walkers and hopes to raise \$260,000. Walkers are encouraged to raise a suggested \$40 contribution. Last year, walkers raised an average of \$189!

Registration brochures are available at the Utah State Chapter, 2995 S. West Temple, Suite C, Salt Lake City, UT 84115, and at the Customer Service Booth/Business Center at all Harmons locations.

To register, participants can: visit www.fightmsutah.org, call the Utah State Chapter at 801-493-0113, mail their registration forms to the chapter, or fax them to 801-493-0122, by Friday, April 9. Registration will also be available at the event the morning of the MS Walk.

ADVOCACY TOOLS: Five Minutes Can Make a Difference

- 1 **Call your legislator.** You don't need a bill number, or a doctorate in health policy. Just tell them what concerns you, what you've read, your latest ideas, etc. And if there is a bill, definitely call them. They would much rather hear from you before the vote than to get an angry call afterwards. They not only welcome such calls, they have staff hired waiting for your call. Get their number from the blue pages in your phone book or go to www.le.utah.gov. If your not sure what to say, visit our Advocacy portion of the Web site go to our link on Calling a Policymaker.
- 2 **Get on the mailing list of an advocacy organization that addresses the issue you care about.** You can join our MS Action Network and learn about upcoming issues, events, research and other upcoming issues in Utah's health care.
- 3 **Inform someone.** Share your concerns with a friend, family member, even someone standing next to you in line. Never underestimate how powerful word-of-mouth can be. It is a small world...you never know who you are talking to.
- 4 **Write a letter to a policymaker.** Writing down your concerns might take more than five minutes, but it is fairly simple. Policymakers expect to receive letters, in many cases they rely on getting information from the public (and they trust you far more than lobbyists). For more information, go to our website and click on the link Writing to a Policymaker.
- 5 **Visit a policymaker.** Honest, this can take less than five minutes. You may get a knock at your door or be greeted coming out of the grocery store during campaign time by a candidate with literature. Don't run away. Take a minute to ask him/her what they would do about your issue if elected. If you want to make an appointment to meet with your legislator, visit our Advocacy portion of the Web site and click on the link Visiting a Policymaker.
- 6 **VOTE.** It is critically important that everyone who is eligible to vote exercises that right. You can do more to support candidates that support the issues you care about.

■ Fundraising
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on our web server. This same area under "My Account" has tools to send out mass emails to invite recipients to either join you on your team, or make a pledge on your behalf (by online "ePledge") by

simply following the link in your email. Take advantage of this great, FREE tool and surpass your fundraising goal in no time at all!

And don't forget to have a little fun with it this year!

Third Party Events

By Courtney Garay

Every year thousands of dollars are gifted through people's great ideas of raising money. Many people who host an event to raise money do so because of the great impact multiple sclerosis has in their lives and they want to commit to the cause, care, and cure of MS.

Any person or company can hold a third party event. It is a creative way to raise money and awareness about MS.

How to get started once you have a great fundraising idea — First, contact Courtney at the chapter to get a form that needs to be filled out. This is a great time to ask questions about doing a fundraiser and get any tips or assistance you might need. Second, gather your company or friends and family together to help you be successful in this endeavor. Third, have a great time doing your fundraiser and involving people in something you believe in. MS is a disease so many have, but so few know much about. By bringing coworkers and loved ones together to learn more and show them how they can make a difference, you are changing the face of MS.

It doesn't matter how much you raise as long as you are raising awareness and have a great time doing so in the process. Here are some successful third party stories...

Shave Steve's Face

Petersen Inc.'s Marsha Porter talked with Steve (a co-worker) about the baby face that had to be underneath all his facial hair. He told her he would shave off his mustache and beard if she could raise \$1,000! After some thought, Marsha started planning for



Getting groomed to fight MS

the Petersen Christmas party fundraiser to shave Steve's face. She first raised \$117 from pocket money at a safety meeting (a lot of money for manufacturing workers to shell out). Then she approached every supplier that walked in the door. By collecting change and checks, they raised well over \$1,000. And Steve shaved his beard for Christmas.

Wasatch MS Ride & Ski

Wasatch MS Ride and Ski was a leadership service project of Erich Fouse. He chose the MS Society to support his boss. Erich's foremost goal was to raise awareness all the while skiing (and riding) in the mountains of Utah. He approached family and friends to each raise \$300 dollars in exchange for a free ski pass, T-shirt, and hat. They all donned their armbands and hit the slopes. Erich used MS Society brochures and a banner to raise awareness. The event raised over a \$1,800 for vital MS research and local programs.

Jim Bouton Speaking Engagement

A past board chair and long time friend of

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■ Third Party Events — *continued from page 12*

the MS Society, Philip McCarthy, planned an exciting and unusual event for Salt Lake City. Jim Bouton, pitcher for the NY Yankees in the 70s, entertained a crowd with baseball stories and why he wrote *Ball Four*, and *Foul Ball*. The luncheon was decorated with peanuts, crackerjacks, and baseballs! It was all the guests could do not to yell “play ball” once Mr. Bouton had finished. This event was a great success raising more than \$1,500!

Although each of these events raised thousands of dollars, don't let that discourage you! Many events like garage sales, home luncheons, or college projects will raise a few hundred dollars. The sky is the limit and every dollar is valuable in the fight against MS. Many programs cost as little as \$250 dollars — so imagine the impact you could have!

Have an idea? Call Courtney at 801-493-0113 or e-mail her at courtney@fightmsutah.org.

How to Take Control of Your Legacy

You've heard about how important it is to have a last will and testament - and maybe you already have one. But think for a moment about why. Perhaps what's most important to you is the fact that having a will ensures your property will pass to those you care about. If you don't leave a will, state law determines how your assets will be divided. It's highly doubtful you would agree to this arbitrary method of choosing your heirs and determining their shares.

An old estate plan can be almost as bad as none at all. Your wishes today for the division of your estate may be quite different from those you had when you made your will. Life events, tax law changes, a move to another state or changes in the nature and value of your assets can also affect your will. To make sure your wishes are followed, you need an up-to-date will.

But there's another reason that a will is important: What you put in your will is what people will remember you by. Your will gives you the opportunity to transfer the values

that are important to you. And one of the best ways to leave a legacy like this is to make charitable bequests in your will.

The Form of Your Bequest

Remembering the National MS Society in your will is a fitting testimony of your belief in our mission. When you name us as a beneficiary, you have many choices. One possibility is a bequest of a fixed dollar amount. Another is to give us a percentage of the estate, which allows you to keep the division of the estate residue in desired proportions, regardless of its size.

Your gift can be contingent. That is, the funds would go to some individual if that person survives you. If not, they would be paid to the Society. A gift without restrictions is usually the most useful, because it allows us to apply the funds to our most pressing needs. But you also can restrict your gift by specifying in your will how the funds are to be used. If you wish to do so, we urge you to consult us before you execute your will to

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Long-term Care Planning...Making Informed Choices

By Dorothy E. Northrop, Director of Clinical Programs, National MS Society

Long-term care refers to a range of supportive services required by individuals who have lost certain functional abilities. Assistance may be needed for Activities of Daily Living (ADLs) such as dressing, bathing, transferring, walking, or toileting, or for Instrumental Activities of Daily Living (IADLs) such as meal preparation, grocery shopping, light housework, managing money, or laundry. Long-term care takes place in many settings (the home, day programs, assisted living facilities, and nursing homes) at any age and is provided by both formal and informal caregivers.

Long-term care used to be equated with nursing home care, but this is no longer true. It now refers to a range of services in a range of settings through a continuum of care. It is an active term. Long-term care services maximize health, maximize functioning, and maximize quality of life.

Multiple sclerosis is a variable and unpredictable disease. The future is often

unknown. With this kind of uncertainty it is important that people with MS try to avoid potential crises by looking to the future and carefully considering how they might meet long-term care needs, should they arise.

Choice and consumer direction are becoming the operative words in the arena of long-term care. However, such opportunities require knowledgeable consumers who can make decisions, plan services, and oversee their care needs.

There are six important areas where knowledge is critical:

Know Your Disease

You must be an educator on MS as a disease, as well as your personal course of MS and the needs that it generates. A health care journal can be a helpful tool to monitor one's health and well-being, and a frank and open discussion with your physician can be helpful in anticipating long-term medical needs.

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■ Controlling Your Legacy — *continued from page 13*

make certain the conditions are ones we are able to meet.

Get Sound Legal Advice

When the time comes for your will to be probated, you won't be here to correct any misunderstandings. To avoid trouble for your heirs, be sure to seek the counsel

of an attorney who specializes in probate and estate planning.

If you're planning to create a deferred gift to the National MS Society, we would be happy to work with your attorney and financial advisors to find the method that works best for you. Please contact Courtney at 1-800-FIGHT-MS or courtney@fightmsutah.org for more information.

■ Long-term Care Planning
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Know Your Support System

You need to carefully consider your family, friends, and neighbors in terms of anticipated long-term care needs. How available are they, or will they be? What is their willingness and reliability? What other life demands are competing with your needs? What is their health status? Age? Life goals?

You also need to look at the formal options of support that are available—state and county home care and respite programs, community providers of support services, VA programs, paratransit services, etc. Become an "educated consumer" when your existing needs do not require these services. Make a file on these programs for future reference.

Know what Adaptive Equipment and Assistive Technology is available

How accessible is your home? What adaptations and technological supports could compensate for some of your functional losses? How much will they cost?

Know the Pro's and Con's of Long-term Care Settings

Home Care: Many services can be brought into the home that can support family living. However issues such as the shortage of home health aides, the cost of such aides, the difficulty of accessing services in rural areas, and home safety must be considered.

Adult Day Programs: Day programs are usually located in the community and are relatively low cost. They provide socialization for the participant as well as respite for the caregiver. However, many are elderly focused, wheelchairs and incontinence may be a challenge, and transportation can be problematic.

Assisted Living: Assisted living provides housing as well as supervision, personal care services, meals, and recreational activities. However, it is expensive, usually elderly focused, and often lacks medical supervision and oversight.

Nursing Home Care: Nursing homes provide 24-hour skilled nursing care for complex, unstable conditions. However, most are elderly focused and may not be providing programming appropriate for the younger resident with MS.

Know Your Financial Situation

Long-term care services are expensive. It is important to know your income resources, assets, and all sources of financial support. It is also important you maximize resources through tax benefits, trusts, asset protection, and Medicaid spend-down if appropriate.

Know Yourself

This is probably the most important area. What is really important to you? Independence or safety? Self-sufficiency or being cared for? Privacy, or being with people? What interests and activities do you want to preserve? What gives your life meaning?

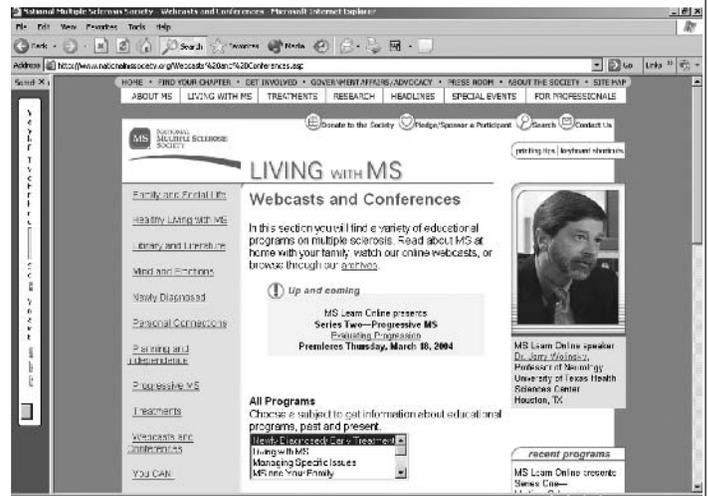
When you have the knowledge that is necessary, then you are ready to move forward, make choices, and avoid crises. Use professionals in your community such as certified financial planners, elder law attorneys, and care managers to help you in this process. If you can anticipate your needs and engage in this process of information gathering and planning, you take ownership of your future, reduce your medical and financial risk, and will know that you have done all that you can to assure your security, autonomy, and quality of life.

MS Learn Online

Providing Quality Information and Convenient Access

Since its first broadcast in 1999, MS Learn Online, the National MS Society's Internet program, has been a successful way to educate people about multiple sclerosis. Hundreds of people, at times thousands, tune into each live or archived program to learn more about MS from the convenience of their own computers. Programs cover a wide variety of topics such as information for people newly diagnosed, employment, intimacy, care-partners, alternative therapies, and progressive MS.

For more information, or to check the MS Learn Online 2004 Program Schedule



go to the National MS Society website, nationalmssociety.org click on "Living With MS" then scroll down to "Webcasts and Conferences".

Could a Complementary Therapy Be Right For You?

Complementary and alternative medicine (CAM) includes everything from exercise and diet to food supplements, stress management strategies, and lifestyle changes. These therapies come from many different disciplines and traditions—yoga, hypnosis, guided imagery, relaxation techniques, traditional herbal healing, Chinese medicine, macrobiotics, naturopathy, and many others. They are referred to as complementary when they are used in conjunction with conventional medical interventions, and alternative when they are used instead of conventional treatments.

CAM appeals to a growing number of Americans. Recent studies indicate that

about 75% of people with MS use some form of CAM. People who are considering CAM should ask the following questions: What does the treatment involve? How and why is it supposed to work? How effective is it? What are the risks? How much does it cost? While keeping in mind the following: Keep your physician informed. A physician caring for a person



continued on following page

■ **Complementary Therapy**
— *continued from page 16*

with MS needs to know all therapies that are being tried. The physician can also alert a person with MS to possible side effects or drug interactions. Don't abandon conventional therapy. Use alternative therapy in addition to, not in place of, conventional therapy. Document the experience. Keep a detailed log of what was done or taken and any changes noted.

For more information on CAM , visit us online at www.nationalmsociety.org in the "Living With MS" section, or call (800) FIGHT-MS.

Watch for future issues on complimentary and alternative medicine!

New Publication Available

“Preventive Care Recommendations for Adults with MS” is a checklist of medical tests that people with MS should remember to include in their medical agendas. It also includes information on immunizations, and suggestions for general health and safety. This publication is a part of the “Basic Facts Series.”

Call the chapter at 1-800-FIGHT MS for a copy or you can also access the PDF file by going to www.nationalmssociety.org, click on “Living with MS”, then “Library and Literature”, then “Brochures”, then “Staying Well.”

Self-Help Group Leaders Needed Statewide!

Contact Jessica Strong at 801-493-0113 or jessica@fightmsutah.org for more information.

Tributes & Memorials

In Memory Of

By

Anna Rosekelly Pool	Ms. Cosette B. Joesten Mr. Richard Johnston
Curtis Deo Steiner	Ms. Colene Clouse Ms. Norma Southern
Dawna Bergstrom	Mr. Roy L. Taylor Steven Andreasen Rose Park Lions Club
Erma Campbell	Mrs. Marilee S. Edwards
Judith Wiley	Mr. and Mrs. T. N. Marks Mr. and Mrs. Alan Engen
Kyle Polychronis	Mr. and Mrs. Dean Jensen Jardine Petroleum Mrs. Suzy Mihalopoulos
Therma Viselli	Mr. and Ms. Brent Viselli
Scott Brown	Ms. Katie C. Kiernan
Von Adamson	Mrs. Anne L. Moss
Mr. John Shuff	Salt Lake Magazine

In Honor Of

By

Ann Brown	Calvan Gould
Natalie Hunter	Ms. Mary Hofeling
Randy Radant	Ms. Kathryn J. Schwartz
Richard Hurty	Mr. William A. Gibbons
Susan J. Holt	Ms. Mary W. Behrens

What's New for Children with MS and Their Families

Young Persons with MS: A Network for Families with a Child or Teen With MS is a support network that provides multiple program options for families living with a child or teen who has been diagnosed with multiple sclerosis. This program is a collaborative effort between the National MS Society and the MS Society of Canada. Together we recognize the unique needs of these children and realize that their parents and siblings may need a variety of support services and programs.



The network targets two distinct populations:

- Children with MS (Under 21)
- Parents of a child or teen with MS

Network Programs

- **Parent Teleconferences**
Teleconferences featuring specialists in the field of pediatric MS are offered for parents every other month. Topics typically relate to research, treatment, cognitive issues, and children's rights within their school system.
- **Parent Support Groups**
A professionally led support group is offered via the telephone for parents interested in talking with other parents about multiple aspects of having a young person with MS.
- **E-mail Group**
The Network connects parents through an e-mail list group where they can share concerns and information, and develop a support network.

- **Short-Term Counseling**
A licensed social worker is available to provide short-term telephone counseling at no cost to families living with a child with MS.
- **Parent Handbook**
Kids Get MS Too: A Guide for Parents Whose Child or Teen has MS, is now available. This handbook contains articles on a variety of topics written by specialists in childhood MS.

Available Soon!

- **Teen CD**
An interactive CD dealing with issues specifically for teens will be coming out this winter.
- **Children Under 13 Workbook**
The book will include educational games, activities and age appropriate articles to help children better understand their diagnosis.
- **Peer Support for Parents**
A Peer Support Program matching parents who have a child diagnosed with MS to act as mentors to other parents who are in the process of adjusting to MS will be established this fiscal year.

Parents can receive information about MS and local resources from the chapter by calling 1-800-FIGHT MS. For information more specific to childhood MS, or to join the Network for Families, parents can contact: Susan Gass, Special Project Consultant, National MS Society
childhoodms@nmss.org
 1-866-KIDS W MS (1-866-543-7967)

AREA	TIME	LOCATION	CONTACT
Bountiful	3rd Tuesday 6:30 - 8:30 p.m.	Davis County Library 725 S. Main	Diana Haslam 801-295-1558 NEED NEW LEADER
Cedar City	3rd Saturday 10:00 a.m.	Chamber of Commerce (Enter west doors)	Linda Lohrengel 435-586-8001
Logan	1st & 3rd Saturday 1:00 - 3:00 p.m.	Independent Living Ctr. 1095 N. Main Street	Sally Anderson 435-752-8270
Moab	2nd Thursday 7:00 p.m.	Community Center Legion Room	Phil Roy 435-259-6759
Orem/Provo	3rd Thursday 7:00 p.m.	Northwest Plaza #6 1134 N. 500 W.	Jill Anderson 801-592-4507
Price	1st Tuesday 7:30 p.m.	Health Department 28 S. 100 E.	Danny Velasquez 435-637-0712
Salt Lake open support	2nd & 4th Wednesday 1:00 p.m.	Utah State Chapter 2995 S. West Temple	Jessica Strong 801-493-0113
Salt Lake beyond ms	Every Wednesday 7:00 p.m.	Utah State Chapter 2995 S. West Temple	Dick Hunter 801-278-4555
Sandy	3rd Thursday 7:00 - 8:30 p.m.	Sandy Library 10100 S. 1450 E.	Donna Liebrecht 801-561-4364
St. George	4th Saturday 10:00 a.m. - 12:00 p.m.	Knight Education Ctr. 300 E. 600 S.	Ruby Edmondston 435-674-3533 or Carla Vierheilig 435-878-2777
West Valley	2nd Thursday 5:30 p.m.	IHC: 4646 W. Lake Park Blvd.	Donna McCormick 801-292-7951 or Bob Garn 801-594-7999
Vernal	3rd Tuesday 6:30 - 7:30 p.m.	Vernal City Offices	Vernie Heeney 435-789-1903
Salt Lake	Physical Therapy Tues/Thurs	Health South 8074 S. 1300 E.	DeeDee Fox 801-493-0113
	Physical Therapy Avail. M-W-F	University of Utah	DeeDee Fox 801-493-0113
Orem/Provo	Physical Therapy Tuesday 10:00 a.m.	Orem Sports Ctr. 459 W. Center St.	DeeDee Fox 801-493-0113

Memorials & Tributes Program at the Utah State Chapter

The National MS Society Utah State Chapter appreciates your contribution to help expand the research and programs available to help people with MS and their families and friends.

I (we) wish to support the Utah State Chapter with a gift of \$ _____

Name: _____

Method of Payment:

Address: _____

Check enclosed. (Make checks payable to the National MS Society)

Phone Number: _____

VISA MasterCard Amex

E-mail: _____

Name of Cardholder: _____

In memory of: -or- In honor of:

Account # _____

Exp. Date: _____

Please send notice of this gift to:

Signature: _____

Enclosed is my company's matching gift from:

I have made charitable giving plans through my will, trust, or life insurance arrangements.

I would like information on charitable giving plans.

Please send me an invitation to the Discovery Circle.

Please send me information on volunteer opportunities at the Utah State Chapter.



NATIONAL
 MULTIPLE SCLEROSIS
 SOCIETY

Utah State Chapter

National Multiple Sclerosis Society
 Utah State Chapter
 2995 South West Temple, Suite C
 Salt Lake City, Utah 84115

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