Summer 2007



Utah State Chapter

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The Utah State Chapter Financial Assistance Program – Help is on the Way









he Financial Assistance Program is intended to assist individuals living with multiple sclerosis to maintain dignity and independence. The Utah State Chapter has expanded the Financial Assistance Program this year in order to provide limited assistance to address emergency needs that affect the physical, environmental and/or emotional needs of an individual with MS. Individuals with MS often have limited financial resources to help access items and/or services to enhance their lives and help them maximize their independence. Our Financial Assistance Program is available to individuals with MS across the State of Utah and is intended to be a "help up" in a time of need.

Items covered by the Financial Assistance Program are: Durable Medical Equipment, Auto or Home Modifications such as hand controls and ramps, Utility Bills (past due gas and electricity), Air Conditioners, Short term Respite/Home Nursing Care, Chore Service, Transportation, Shortterm Counseling, and Miscellaneous items (determined on a case-by-case basis). Payment is made directly to the provider.

Funding Guidelines:

- Financial need
- The need is related to effects of MS
- Short-term assistance may help a person hold on to an asset long term
- Purchase or repair of a durable item will enhance independence, safety or comfort
- There is no other possible resource for the item or service
- The item will help to relieve family caregiver burden
- There is a \$500 cap per person/per year

Application Process:

- Completed financial assistance application
- Written verification of MS diagnosis from doctor.
- Supporting documentation as needed

If you would like more information on the Financial Assistance Program please call: 1-800-344-4687, option 1 or e-mail Clare Wright at <u>clare.wright@</u><u>nmss.org.</u>



Ask The Neurologist

Series Through Fall 2007

A local MS Specialist will discuss late breaking information about MS. The remainder of the time will be for your questions. There will also be a brief 10 minute MS presentation by Teva Neuroscience.

Agenda: ____

6:00 - 6:30 p.m. Arrival and Dinner

6:30 - 6:40 p.m. Brief Presentation - Teva Neuroscience6:40 - 6:50 p.m. Late Breaking Information - MS Specialist6:50 - 7:40 p.m. YOUR QUESTIONS for the Neurologist

This will be a complimentary program with dinner provided. **Please RSVP to: 1-800-877-8100, option 3.** Please state which programs you will be attending, along with your name and phone number. Seating will be limited and taken on a first come first serve basis.

Please Join Us!

CHAPTER NEWS

Inside Out a Success!

n March 24, nearly 100 women gathered at Salt Lake Community College for the Utah State Chapter's first ever conference for women. After registering, the ladies listened to a presentation by Pat Kennedy, RN, on several topics that "you don't want to ask your male Neurologist". Pat covered topics such as bladder control, sexual issues in MS, and pregnancy. During a break, a chocolate fountain flowed and participants had the option of dipping fruit, pretzels, and other snacks.

Two breakout sessions were held with an option of three topics: Depression and MS by Eve Sanford, Energy Conservation by JoAnne Wright, and How to Talk to Your Doctor by Pat Kennedy. A delicious lunch

Dates:

Salt Lake City:

Tuesday August 28th	Dr. Duvernay and Dr. Skuster
Wednesday, September 26 th	Dr. Elena James
Tuesday, October 30th	Dr. John Steffens
Tuesday, November 27th	ТВА
Location: Marie Callendar's	1100 East 3900 South
Northern Utah:	
Wednesday, September 12th	at 12:00 Noon
Location: Melina's Restaura	nt

855 W. Heritage Park Blvd, Suite 1, Layton, Utah

of lemon chicken, potatoes, salad, and rolls was served. During lunch, a resource fair was available offering local services such as travel for people with disabilities, housing modifications, and recreational trips. There were also local vendors offering free massages, hair styles, or nail painting.

The final keynote presentation was given by Matt Townsend on Relationships. His witty humor and tell-all approach was eagerly accepted and he had the room laughing in no time. A prize drawing was held with items donated from local businesses. Women left the conference feeling uplifted, refreshed, and rejuvenated. If you missed this great program, be sure to keep an eye for it again next year!

We would like to thank our program sponsors; Teva Neuroscience, Biogen, and Serono.

CHAPTER NEWS

Upcoming events

Harmons MS Bike Tour June 22 – 24 – Cache Valley Fairgrounds Logan, Utah

MS 101 Newly Diagnosed Forum July 11 – 6:00 p.m. Teleconference, statewide

River Trip with Common Ground Adventures July 28 – 29 – Jackson Hole, Wyoming

Dinner for Two

August 2 - 5:30 p.m. - 8:00 p.m. Rodizio Grill, Salt Lake City, Utah

JumpStart in collaboration with the Huega Center

August 18 – 9:00 a.m. – 3:30 p.m. Radisson Hotel, Salt Lake City, Utah

Long Term Care Seminar

August 24 – Details Coming Soon Ogden, Utah

MS 101 Newly Diagnosed Forum

September 6 – 12:00 p.m. Utah State Chapter, Salt Lake City, Utah

Dinner of Champions September 12 Salt Lake City, Utah

Couples Retreat

September 21 - 22 – Details Coming Soon Salt Lake City, Utah

Mobility Program

September 26 - St. George, Utah September 27 - Cedar City, Utah

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801-424-0113 / 800-344-4867

Publication of the National MS Society Utah State Chapter 6364 S. Highland Drive, Suite 101 Salt Lake City, Utah 84121

The National MS Society does not endorse products, services, or manufacturers. Such names appear here solely because they are considered valuable information. The National MS Society assumes no liability for the use of contents or any product or service mentioned.

Information provided by the Society is based upon professional advice, 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.

MS stops people from moving. The National MS Society exists to make sure it doesn't.

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Help the Utah State Chapter Raise Money!

he thought of helping others is one we all have but the action may require more time or money than we can afford. Fortunately, there is now a solution and its simplicity makes it perfect for those struggling with MS, caring for loved ones with the disease, and the many who want to help.

GoodSearch is a Yahoo powered search engine that donates one penny of every search you run to your charity of choice. The Utah State Chapter of the National MS Society is now set up to be a part of this wonderful ongoing fundraising effort.

Getting started is as easy as making GoodSearch your homepage, adding it to your bookmarks/ links, or adding the GoodSearch toolbar to your browser. Just go to <u>www.goodsearch.com</u> and be sure to enter 'National Multiple Sclerosis Society-NMSS-Utah State Chapter' as the charity you want to support. Just 500 of us searching four times a day will raise about \$7,300 in a year without anyone spending a dime. Be sure to spread the word!

CHAPTER NEWS

Men's Night Out with the Utah Jazz

n April 14 men with MS in Utah were treated to a night out at a Utah Jazz home game for the Utah State Chapter's annual Men's Night Out program. The program included a research update and question and answer session by Dr. John Rose.

A delicious dinner of prime rib was served while participants were able to mingle and chat. Men watched as the Utah Jazz took on, and beat, the Houston Rockets in the final home game of the season. The Jazz Dancers and Jazz Bear even paid a visit to the Utah State Chapter's private box.

Participants had a great time at this annual favorite for men with MS. We would like to thank our sponsors: Biogen, Teva Neuroscience, and Serono.

Family Day 2007

amily Day is a family favorite at the Utah State Chapter. This year's was no exception! The Chapter sponsored a night out with the Salt Lake Bees for people with MS and their families. Nearly 600 people turned out for the event. A scrumptious dinner of hamburgers and hot dogs was provided before the game. Children and adults alike were wowed by a magician and were able to take

home a souvenir balloon animal or hat.

Noel Carlson, an MS researcher at the University of Utah threw out the ceremonial first pitch. The Salt Lake Bees played a good game and defeated the Memphis Redbirds with a final score of 11 to 3. We would like to thank our sponsors: Bayer and Serono.



"Attendees enjoying the days festivities"

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From the Chairman of the Board

Dear Members,

t is an extremely exciting and pivotal time for the National MS Society. Over the past year, volunteer and staff leaders at the Society have developed a new Strategic Response, which outlines a new direction for the MS Society that will strengthen our efforts and move us faster toward a world free of MS.

To move forward in the fight against MS:

- We will be a driving force in MS Research, relentlessly pursuing prevention, treatment and a cure.
- We will address the challenges of each person who is affected by MS.
- We will mobilize the talents and resources of the millions of people who want to do something about MS.
- We will be activists.
- We will raise a total of \$1.25 billion nationally by the end of year 2010 to fight the disease.

In creating this response, members of the Society agreed that regardless of how MS impacts people and their families, we will respond in a way that is:

Bold:

We will set high standards and expect to reach them and we will welcome innovation in research, programming, advocacy and fundraising.

Relevant:

When people turn to us for help, we

will respond in a way that is tailored to their individual needs.

Inclusive:

We will recognize and embrace other people who are engaged in the fight against MS, even when they work outside of the Society's umbrella.

Transparent:

We will maintain the highest standards of accountability.

Engaging:

We will engage those who want to do something about MS new and will consider different ideas even when they challenge our own experiences.

Our Strategic Response calls for us to be BOLD, RELEVANT, INCLUSIVE, TRANSPARENT and ENGAGING so we can fuel a much more aggressive, and inclusive, movement against MS on a much broader scale (clinical research, and programs for those diagnosed throughout the continuum of a diagnosis). The first letters of Bold, Relevant, Inclusive, Transparent and Engaging, create the acronym "BRITE." This is no coincidence. The National MS Society will continue to gain momentum toward the day when we will live in a world free of MS. A day that will most certainly be bright!

· A.H.

Cecil Hedger, Chairman of the Board

Relationship Matters: A Program for Couples Living With MS

aving a satisfactory relationship is hard work even in the best of times. MS can make it even harder because the disease can often be unpredictable. The Utah State Chapter is excited to be a part of an exciting new program specifically designed to help couples negotiate and manage this uncertainty, *"Relationship Matters: A Program* for Couples Living with MS".

The *Relationship Matters* program exists to help you and your partner minimize the impact of MS on your lives through a creative mix of interactive courses. The *Relationship Matters* program helps couples learn and apply skills to deal with challenges related to MS through the following classes:

• Communications and Conflict Resolution: Facing Opportunities and Challenges Together

Enhance your communication and conflict resolution. Learn how to effectively communicate on even the most difficult issues.

Adapting: Financial Planning for a Life with MS

MS can be an expensive disease. Learn the basic steps of planning for a financial future that includes MS.

Career Crossroads: Facts and Fiction

Employment concerns create stress, and MS can exacerbate those concerns. Learn how to manage potential employment issues as a couple.

Having Fun Together

MS may interfere with the things you enjoy doing as a couple. Learn how to still have fun in new and adaptive ways.

Intimacy: Enriching your Relationship

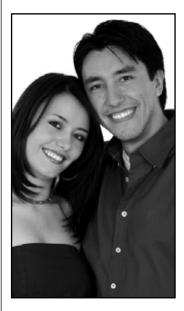
Talk about the tough issues that can get in the way of true intimacy. You will learn creative ways to address and overcome these issues in your relationship.

When you know how to take charge as a couple, MS doesn't have to rule your relationship. Working in collaboration with a MS Navigator, you and your partner will create a personalized education plan. Through participation in the program, you will acquire the skills of effective communication to manage the effects of MS on your relationship. Registration for the program is ongoing. For more information please call 1-800-344-4867 or e-mail: <u>couplesprogram@nmss.org</u>.

The Utah State Chapter will host a weekend retreat for couples living with MS on September 21-22, 2007 in Salt Lake City. Overnight accommodations, meals, and workshop materials will be provided. This fun and informative in-person workshop is facilitated by relationship experts Len and Cheryl Chatman, a couple living with MS. Registration for this program will begin August 20, 2007 online or by calling 1-800-344-4867, press option 1. Program sponsors: Teva Neuroscience and Serono Pfizer.

Funding for this project was provided by the United States Department of Health and Human Services, Administration for Children and Families, Grant: 90FE0090/01.

CHAPTER NEWS



Dinner for 2: An Evening for Young Adults with MS

Are you ages 18-30 looking to meet other young adults with MS? Join the Utah State Chapter for it's first ever "Dinner for 2" Program. Mark your calendar, grab a friend, and join us! Married and singles welcome.

Thursday, August 2, 2007 Location: Rodizio Grill,Trolley Square, Salt Lake City 5:30 – 6:30 p.m. Meet & Mingle 6:30 – 8:00 p.m. Dinner

Registration for this program will begin July 13. Register online at <u>www.fightmsutah.</u> <u>org</u> or by calling 800-344-4867, press option 1.

WELLNESS PROGRAMS

MS Exercise Programs

The Utah State Chapter has partnered with you local communities to offer exercise programs. You should only begin an exercise program under the care and guidance of your physician or a physical therapist. Call the Chapter for further information. All locations are \$20 per month.

Physical Therapy

University of Utah Salt Lake City Mon, Wed, Fri 8:00 a.m. – 12:00 p.m. Health South Sandy Tuesday or Thursday 11:00 a.m. – 12:00 p.m.

Sports Medicine Center Orem Tuesday 10:00 a.m. – 12:00 p.m.

Aquatics

The following are community classes with instructors knowledgeable about MS. For more information please contact the facilities directly. Steiner West Pool at 801-974-2420, Roy Recreation Complex at 801-774-1050.

Steiner West Pool

855 W. California Ave., West Valley City, UT 801-974-2420 Tuesday & Thursday 5:00 p.m. - 6:00 p.m. Cost: \$22.50 for a15-class punch pass

Roy Recreation Complex

2150 W. 4700 S. Roy, UT Monday & Thursday 7:30 p.m. – 8:15 p.m. Cost: \$2 per person per class

Self Help Groups

Before you choose a group, ask yourself what group atmosphere you feel comfortable with and what you'd like to gain from participation. Each group is unique and open to everyone; those with MS, spouses, family and friends! Please contact the group leader (listed) before attending a group to ensure the correct time and location of the group. If you can't find a group to meet your needs, contact the Chapter to start your own group.

Northern Utah Ogden

2nd Tuesday 11:00 a.m. Roy Library 1950 W. 4800 S. Barbara 801-731-7088 Joyce 801-547-9840

Logan

3rd Saturday 1:00 – 3:00 p.m. Independent Living Center 1095 N. Main Street Sally 435-751-8270 Monica 435-245-4919

Central Utah

No groups at this time

Salt Lake Area Bountiful

Scrapaholics 3rd Wednesday 6:30 - 8:30 p.m. Davis County Library 725 S. Main Street Julie 801-951-1507

Beyond MS

Wednesdays 7:00 p.m. Utah State Chapter 6364 S. Highland Dr. Beverly 801-280-4480 Cheryl 801-886-0256

MS - Multiple Survivors

3rd Thursday 4:00 p.m. Intel Corporation 3740 W. 13400 S. #116 Lori 801-580-7885

Child or Teen w/MS

2nd Saturday 10:00 a.m. Call for location Lynne 801-832-0173

West Valley Area

2nd & 4th Thursday 6:30 – 8:30 p.m. St. Stephens Episcopal Church 4615 S. 3200 W. Dan 801-965-6885

Eastern Utah Price

1st Tuesday 7:30 p.m. Health Department 28 S. 100 E. Danny 435-637-0712

Vernal

3rd Thursday 6:30 – 7:30 p.m. Vernal City Offices 447 E. Main St. Vernie 435-789-1903

Southern Utah St. George

4th Saturday 10:00 a.m. Knight Education Ctr. 300 E. 600 S. Ruby 435-674-3533

Cedar City

3rd Saturday 11:00 a.m. Chamber of Commerce 581 N. Main St. (Enter west doors) Linda 435-586-8001





JUMPSTART your health with the National Multiple Sclerosis Society and The Heuga Center s can do approach. FREE one-day JUMPSTART workshop,

Saturday, August 18, 2007 - 9:00 a.m. - 3:30 p.m. Radisson Hotel, 215 West South Temple, Salt Lake City, UT Complimentary lunch will be provided.

Presenters:

John Rose, MD: MS: What to Know and What to Do Pat Kennedy, RN, CNP, MSCN: The Fact and Fiction of Nutrition and Nutritional Supplements

Brian Hutchinson, PT, MSCS: Physical Activity and MS: What We Know Dave Engstrom, PhD: How to Get and Maintain Motivation

Space is limited. To register today, call 800.344.4867 or visit www.fightmsutah.org.



PROMOTING HEALTH, CREATING HOPE



This free JUMPSTART Program is made possible by Teva Neuroscience Inc., Bayer HealthCare Pharmaceuticals and The Athwin Foundation.

ADVOCACY

MS ACTIVISTS' INFLUENCE GROWS

More members, more calls

Our nationwide network of MS activists has increased by more than 80% this year. That means members of Congress have heard from more MS activists on more MS issues than ever before. MS activists made more than 64,000 calls and e-mails to their legislators so far this year. That is almost double the number of contacts made in all of 2006.

Does it work?

With the help of these calls and emails, the Lifespan Respite Care Act passed the U.S. House and Senate last year. Signed into law in December 2006, the act provides almost \$300 million over five years for competitive grants for states to increase the availability of respite care services for family caregivers of an individual with special needs regardless of age.

On our agenda

- Support for funding MS research through the Department of Defense is growing impressively
- Legislators who are on one of the Appropriations Defense Subcommittees are currently being contacted
- Activists will be on hand at the Iowa, New Hampshire, and other presidential primary stops to question candidates about health care, prescription drug coverage, and more

Get updates online

It's easy to get involved. Sign up at <u>nationalmssociety.org/advocacy</u>. We'll send updates on news from Washington, hot issues, and ways to take action. As an MS activist, you'll help ensure that our volunteer work, research investment, and programs are supported by laws and regulations that make sense.

Get involved on a local level by joining the Action Alert list. You will receive e-mail updates on state issues that impact individuals with MS and information on ways that you can take action. To join, visit <u>www.</u> <u>fightmsutah.org</u> and click on the Advocacy tab.

Become an MS activist. Join the movement.



ADVOCACY

NATIONAL RESEARCH STUDY NEEDS VOLUNTEERS

The Sonya Slifka Longitudinal MS Study, sponsored by the National MS Society, has collected information from some 1,600 people with MS since 1999. Because the Slifka Study provides such valuable information to the MS community, it has just been expanded and extended for another five years. Now it needs 2,500 more people with MS.



Beverly, diagnosed in 2001

Specific populations with MS will be "oversampled" in this phase of the study to ensure that their experiences are adequately represented. The target populations are African-American, Hispanic, and people diagnosed with MS after September 2006.

Most participants will be selected at random from the National MS Society's database. However, to ensure that the study adequately covers people with MS who are African-American, Hispanic, and/or are very recently diagnosed, we are asking for volunteers. If you are a member of one or more of these groups, please consider joining this important study. Call 1-800-305-8013. Participation involves telephone interviews every six months, plus keeping a log of your health status, the medical services and therapies you use, the money you spend on MS-related needs, and the impact MS has on your life. The calls are made in English, so volunteers need to be comfortable talking on the phone in English.

All the information collected is confidential. Reseachers use data from the study will not be able to identify individual participants.

MS researchers are already using data from the first phase of the study to identify ways to improve quality of life and manage MS symptoms more effectively. The study data also helps the Society advocate for public policies that address the issues most important to people with MS.

The second phase of the study will lead to more important information about how people live with MS over time.

Sonya Slifka and her son Richard The Sonya Slifka Longitudinal MS Study is supported in part by a generous gift from the Society's past National Chair, Richard Slifka, and in part by the Society's Promise: 2010 campaign. The study is named for Richard's mother, who developed MS when he was still a boy. The grown-up Richard Slifka has been a leadership volunteer for the Central New England Chapter for more than 25 years as well as serving on the National Board since 1988. He has generated more than \$3 million in personal donations and solicitations.

LIVING WITH MS

THE MS TECHNOLOGY COLLABORATIVE: MAKING TECHNOLOGY WORK FOR YOU

The new MS Technology Collaborative wants to raise awareness of how technology can help people with MS live well. It wants to break down barriers for those who aren't comfortable using technology and educate people on how to choose, use, and maximize the impact of technology on their lives no matter how MS affects them. The collaborative plans to

- Explore how people with MS currently use technology, including computers, cell phones, PDAs, and Web communities;
- Identify techniques and applications that can solve individual problems;
- Increase everyone's awareness of available solutions; and
- Develop new solutions to fill in the gaps.

Visit mymsmyway.com to learn more.

Access for all

The MS Technology Collaborative is a unique initiative by the National MS Society, Microsoft, and Bayer Healthcare Pharmaceuticals, a division of Bayer Schering Pharma AG (formerly Berlex). The three partners are creating a future where technology can be used by anyone living with MS. That includes people who have blurred vision, uncooperative fingers, iffy memories. It includes those who are newly diagnosed or have progressing MS-related symptoms. The MS Technology Collaborative is founded on the belief that improved technology can help people with MS move their lives forward. From telephones to global positioning systems, technology provides access to the world—offering entertainment, education, employment, and personal connections.

Technology has even more potential for those living with MS. Health-care systems will increasingly use computer communication for partnerships in self-care and health education. Soon computer use may be a link to healthy living with MS.

Preparing the way

Before <u>mymsmyway.com</u> went live, the collaborative first formed a steering committee of diverse people living with MS across the country. That committee is providing ongoing input. Next, the collaborative fielded a nationwide survey to get the big picture into focus: What is the role of technology in the lives of people with MS?

The survey asks pointed questions about how people currently use technology, what limitations they experience, and whether technology helps them to live better. Survey results will be posted on both <u>mymsmyway.com</u> and the Society's Web site as soon as analysis is final.

The MS Technology Collaborative hopes to develop a personalized, interactive Web experience that can deliver information tailored to the needs of a specific individual. Just how that will work is very much a work in progress.

Be part of the future. Visit <u>mymsmyway.</u> <u>com</u> today, and join in.

COOL TIPS FOR HOT DAYS

Avoid the hot seat

Keep your car cooler with reflective shades for the windshield and fabric car seat covers. Available at auto supply stores.

The Ability Foundation Technology Assistance for Persons with Disabilities

Founded in Utah in 1993, Dr. Ernest and Anneke Robison created the Ability Foundation based on their experience of parenting a severely disabled son. Their son passed away in 1999 at the young age of ten. Their experience has allowed them to develop an empathy and understanding of the stresses, challenges, and needs of individuals with disabilities and their families. One of the goals of the Ability Foundation is to "intentionally streamline the process to provide service with the least stress to the client." Dr. Robison's education and professional training, together with his firsthand experience with a disabled son, has given the Ability Foundation a unique perspective on the needs of people with disabilities as well as skill for adapting and modifying equipment for specific individuals. With his expertise leading a skilled team, the Ability Foundation is also actively involved in designing and developing new equipment to expand the quality of life for those who are disabled.

The Ability Foundation donates equipment to individuals across all disabilities on a first come, first serve basis, regardless of location of residence, race, religion, income, or social status. They serve clients directly and indirectly, working jointly with service providers before placing equipment. They also work with individuals who will use the equipment to ensure that it is placed appropriately and used properly. Where it is possible, equipment is customized to fit the needs of specific individuals. In 2006, 97% of equipment was donated free of charge with more than \$145,000 in service and equipment.

Of those assisted approximately 400 individuals were through direct client contact and more than 1,000 individuals through other service organizations. While the Ability Foundation primarily serves individuals in Utah and the intermountain west, they also serve individuals in other states and several foreign countries.

The Ability Foundation receives inkind donations of new, damaged, and used equipment from other charities, individuals, and businesses. Skilled personnel check, repair, refurbish, and clean equipment before placing it.

The Ability Foundation is a publicly supported charity and receives donations from individuals, other foundations, corporations, businesses and other charities. For more information on the Ability Foundation please visit their Web site at <u>www.abilityfound.org</u>, e-mail them at <u>donations@abilityfound.org</u> or call 801-261-5738.



Multiple Sclerosis

First questions. Then answers.

A trusted resource for people newly diagnosed with MS

Have you recently been diagnosed with multiple sclerosis (MS)? What are your *first questions*? Who can you ask? Are you not even sure where to begin?

A neurologist or other MS specialist is available to discuss common questions about MS. This is your chance to ask, listen, and learn.

The teleconference is held on the first Tuesday and the third Tuesday of each month. Be sure to check the reverse side of this card for the start time from your calling area. No preregistration is required.



You may be feeling overwhelmed, but you're not alone. Get the information you need now.

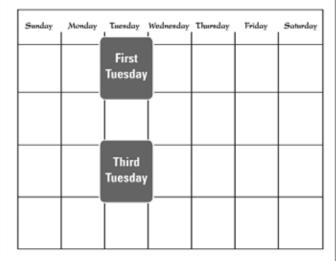
To join the call, dial 1.877.748.8211 ten minutes before the start time on the first or third Tuesday of the month. When asked for a code, please say "MS teleconference." If you need additional information or would like to view optional slides for the program, please visit www.MSActiveSource.com.

This teleconference is sponsored by Biogen Idec.

First questions. Then answers.

Multiple Sclerosis

A trusted resource for people newly diagnosed with MS



Available from July 17, 2007 to November 6, 2007.

To join the call, dial 1.877.748.8211 ten minutes before the start time on the first or third Tuesday of the month. When asked for a code, please say "MS teleconference."

Below please find the start time for your calling area:

First Tuesday	Third Tuesday
7 PM Eastern Time	10 PM Eastern Time
6 рм Central Time	9 рм Central Time
5 PM Mountain Time	8 рм Mountain Time
4 PM Pacific Time	7 PM Pacific Time

For more information about this teleconference, please visit www.MSActiveSource.com.

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biogen idec

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LIVING WITH MS

Nerve pain is different

ll pain is transmitted by nerves, but nerve pain is different. "Phantom limb pain" is a vivid example of "neuropathic" or nerve pain. This type of pain originates in the central nervous system in injured nerve pathways, not in the bones or muscles. A person with phantom limb pain feels pain in a body part



that was amputated in the past.

MS lesions can injure nerve pathways and produce neuropathic pain-or unpleasant sensations called dysesthesias (or "di-es-THESE-ee-ahs"). The burning, aching, stabbing, prickling, or itching may start and stop or drag on. MS lesions

COOL TIPS FOR HOT DAYS

Water and

Keep a plastic water bottle half filled in the freezer. Top it off and you'll have a drink that stays cool all day.



]/

Herbals teas—fruity blends, peppermint, and ginger—are good chilled and have little or no calories if you make your own.

Avoid sugary drinks. They leave you thirstier—and heavier too, because of all the calories.

Drink fruit juice the light way by extending with ice, water, or a fruity herbal tea.

may also cause "allodynia" ("Al-oh-DIN-ee-ah")—which is pain from something that shouldn't be painful. A soft touch, the weight of bed covers, even a cool breeze can be the trigger.

Neuropathic pain is not soothed by the over-thecounter medications that work on muscle pain. Even

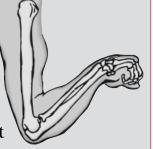
powerful prescription medications such as Percocet, Lortab, Oxycontin, or Darvocet are not effective for this kind of pain.

Instead, physicians need to prescribe medications that work on nerves. They may be anti-convulsants, such as Tegretol, Dilantin, or Neurontin, antidepressants, such as Elavil, or new drugs approved for diabetic pain, such as Lyrica or Cymbalta. It's not uncommon to try out drugs to find what works best.

Muscle and bone pain happen too

People who have difficulty walking may develop pain from the stresses placed on muscles, bones, and joints.

Sitting also stresses body parts. Muscle and bone pain responds to physical therapy and to standard pain medications. A person with MS might have more than one



kind of pain. The first step to pain control is a professional diagnosis.

(continued opposite)

LIVING WITH MS

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■ Nerve pain is different — continued from previous page

Global survey shows communication critical to pain relief

A seven-country survey by Harris Interactive* shows that doctor-patient communication is essential for diagnosis and treatment of nerve—or neuropathic—pain.

The survey found that many general practitioners (family doctors) did not find it easy to recognize this type of pain. The survey also found that people with nerve pain waited from 5.7 to 19.5 months before talking to a physician

Try nondrug approaches right away

While you and your physician investigate medication, pain specialists say it's smart to add complementary therapies right away. Nerves can become used to pain, making the pain harder to control.

Consider relaxation techniques, meditation, guided imagery, selfhypnosis, prayer, or music therapy. Joining a support group, pursuing a hobby, or having a good laugh watching comedy videos are also known to minimize pain.

Experiment with applications of heat, cold, or pressure. Try massage, acupuncture, yoga, tai chi, or physical therapy.

Oddly enough, neuropathic pain does not mean the MS is getting worse. But it could make life worse. about it. Many believed the pain would go away by itself.

Language matters

Success involved two-way communication. People who were able to describe intensity, duration, location, and how a pain feels—and physicians who asked for these descriptions—were far more likely to have successful outcomes. They used descriptive words like dull, throbbing, stabbing, numb, achy, prickly, burning, pins and needles, and shock-like.

The survey contacted approximately 700 people diagnosed with nerve pain because of MS, diabetes, herpes, cancer, stroke, or other conditions and 700 physicians in Finland, Germany, Great Britain, Korea, Italy, Mexico, and Spain.

Tell your doctor

The National MS Society's Professional Resource Center Clinical Bulletin, "Pain in Multiple Sclerosis" by Heidi Malone, PhD, RN, can be downloaded at <u>nationalmssociety.org/PRC</u>. It includes charts on pharmacological management and an extensive bibliography.

If You or Someone You Know Has MS

S tudies 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 <u>www.</u> <u>nationalmssociety.org</u> or 1-800-344-4867 to learn about ways to manage multiple sclerosis and about current research that may one day reveal a cure.

* Funded by the Neuropathic Pain Network and Pfizer, Inc.

MONEY MATTERS

Filing for SSDI Benefits

f you have MS and are unable to work due to an MS-related disability and/or other conditions, you may be entitled to Social Security Disability Insurance (SSDI) benefits. To receive these benefits, you must have worked at least five of the 10 years immediately before the disability and paid FICA taxes. The disability or impairments must be expected to last for at least 12 months.

Step One: Get familiar with the process

See "Loosening the SSDI Knots" in the April-May 2007 InsideMS. Go to <u>nationalmssociety.</u> <u>org</u>, click on Library in the gray menu bar in the upper right hand corner, and then on InsideMS in the box on the left-hand side—or call us for a copy.

For a more detailed review, check out the

Society's new SSDI Guidebook for People with MS at <u>nationalmssociety.org/SSDI</u>. If you do not have Web access, call us.

The exact requirements for SSDI are detailed in the Social Security Administration's Blue Book (SSA No. 64-039, or <u>www.ssa.gov/disability/</u> <u>professionals/bluebook</u>).

Step Two: Get prepared

Keep a detailed journal of your MS symptoms and how they limit your ability to work.

Visit your doctor and let her/him know you plan to apply for SSDI benefits.

Offer your doctor the Society's template letters to make the documentation of your symptoms easier. (Go to <u>nationalmssociety.org/SSDI</u> and scroll down to "Worksheets and Sample Letters.")

Step Three: Strengthen your chances

Don't hesitate to ask for help from an SSA representative, a family member, staff in your doctor's office, or a knowledgeable

Contacting the Social Security Administration

Toll-free: 800-772-1213, 7 AM to 7 PM, M–F Toll-free TTY: 800-325-0778, 7 AM to 7 PM, M–F On the Web: <u>www.ssa.gov</u> Mailing address: Social Security Administration, Office of Public Inquiries, Windsor Park Building, 6401 Security Blvd., Baltimore, MD 21235 person at the Society.

Don't delay if you can't complete certain general information on the application. Sufficient medical information is the most important.

The best source of your medical information is your doctor. Be sure your doctor is aware of all of your symptoms.

Step four: The waiting game

Recent data indicates that nationwide roughly 62% of initial claims for SSDI were denied, and that most applicants who went on to file a written appeal called the "reconsideration" were also turned down. Only 16% of these secondlevel claims were approved.

The third level provides a face-to-face hearing before an administrative law judge called the ALJ hearing. Nearly 60% of recent hearing decisions were awarded to the person seeking benefits.

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MONEY MATTERS

msconnection

Social Security Disability Insurance (SSDI) Information Sessions

The Utah State Chapter is now offering SSDI information sessions on a regular basis.

- Learn about the benefits SSDI provides
- Know what information you will need to complete the application process
- Find out what the next step is if your application is denied
- Ask questions

These programs will be scheduled on an ongoing basis. Please contact Brook to express an interest in attending an information session at brook.osterland@ nmss.org or 801-424-0113, press option 2.

Filing for SSDI Benefits

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A final level is also available: the Appeals Council of the Social Security Administration. This rarely results in an award of benefits. Beyond this point, a person may file a complaint in the U.S. District Court.

Optional: Retain a representative

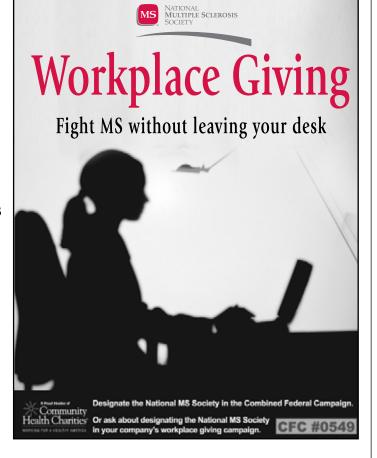
The law permits SSDI applicants to retain a representative on a contingency basis, meaning that the fee is based on the outcome of the claim.

The representative, who may or may not be a lawyer, is a professional with expertise in Social Security rules and regulations. Applicants may pay a representative out of the Social Security benefit check when the claim is approved. The fee will be 25% of the retroactive benefit, but cannot exceed \$5,300.

COOL TIPS FOR HOT DAYS

Tax deduction

With a doctor's prescription, you can claim a new airconditioner as a tax-deductible medical expense. Check with a tax advisor for details. 1111



NEWLY DIAGNOSED

GET GOING WITH TWO NEW RESOURCES

Begin with MS Learn Online

Fearful, depressed, confused? A person can feel all of this after an MS diagnosis. But perspective—and hope—are available in the MS Learn Online webcast *Where do I begin? Newly Diagnosed with MS*.

Three people, with more than 30 years of living with MS between them, talk about their lives and recall their feelings at the time of their diagnosis. They discuss relationships and support, becoming one's own health-care advocate, and the possibility of reinventing oneself while managing life with a chronic illness.

To view the 23-minute webcast and explore the full roster of MS Learn Online offerings, go to <u>nationalmssociety.org/mslearnonline</u>.

KNOWLEDGE is **POWER**

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

This is why we're here.



Society

New! KIP Teleconference Series The Knowledge Is Power home study program (KIP) for people newly diagnosed and their family members answers many questions. But you may still have more. KIP is beefing up by offering a series of free telephone conference calls hosted by MS experts.

Neurologists and other MS professionals will answer questions on topics such as symptom management, relationships, employment, and more. These calls not only provide information, they offer a chance to interact with others who are also facing a new MS diagnosis—all from the privacy of home.

Register for KIP and receive a teleconference schedule as part of this free, six-week course. See ad this page for details.

COOL TIPS FOR HOT DAYS

Dress light and loose

Loose cotton blends and microfiber fabrics allow perspiration to evaporate. Try a wide-brim hat. Canvas or mesh sneakers are cooler than leather.

Cool clothing

Commercial cooling garments, such as vests, bra inserts, and headbands, can help you stay cool for hours. Search ABLEDATA (<u>www.</u> <u>abledata.com</u> or call 800-227-0216) or call us for referrals.

Spray instead

Sweat evaporating on skin is how your body stays cool. Carry water in a spray bottle and wet your shirt and hat for the same effect. Stand in front of a fan for instant A/C.

TEAM MS



Ruth Barrow – A True MS Champion for the MS Walk!

Walk into one Southern Utah MS Walk – Ruth rose to the challenge and mission of the Society to "Join the Movement." Ruth lives in Cedar City and has a desire to help fund vital research and programs for the National MS Society. She knows that contributions received through events, such as the MS Walk, will help to some day find a cure for MS. Ruth set several goals for herself to become involved as a participant in the Southern Utah MS Walk.

First, she wanted to build awareness in her community, so she got on her scooter, "Sassie," to deliver posters and brochures throughout Cedar City. She continued her quest by reaching out to past Cedar City participants and invited them to join the movement. Her next goal, and a very important one, was to physically attend the Southern Utah MS Walk on March 24, 2007. She didn't know if she would be able to make it – but with supportive friends and members of her "Sunshine Pals" team by her side she was able to attend. On Ruth's MS Walk Web site she states "I've registered for the MS Walk because I want to do something for the people who have been diagnosed - and because I want to do everything to prevent more people from learning what it means to live with this disease."

As of the print date, Ruth, her team and supportive friends have raised \$1,970.00 and they haven't stopped! They scheduled a car wash on May 26 at Wal-Mart in Cedar City, so her fundraising will continue to rise. Thank you Ruth for your passion and inspiration - you are one of our Utah Champions!



MS Walk Participants Turn Out in Record Numbers

A HUGE "THANK YOU" to all MS Walkers, donors, and sponsors who hit the roads statewide to "Join the Movement!" We are overwhelmed by your generosity and dedication to create a world free of MS. Participants turned out in record numbers at all five walk sites – Southern Utah, Provo, Salt Lake City, Ogden and Vernal. We especially want to recognize the generous support of our presenting sponsor Questar. They not only contributed financially, but as key volunteers at all walk sites! Thank you Questar!

We want to thank and acknowledge our MS Walk Community Coordinators

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TEAM MS

MS Walk Participants

— continued from previous page

 Christina Hopkinson, Southern Utah; Tim & Wendy Magaw, Ogden; and Vernie Heeney, Vernal; for their commitment, dedication and hours of planning to help make the outlying walks successful. Without each of these individuals, as well as their committee members and numerous volunteers, the MS Walk would not be able to reach out to communities outside the Salt Lake City area. We also want to thank our Salt Lake City MS Walk Committee members: Tonia Davis, Jennifer Kruse, Jan Bates, David Stephenson, Jae Golson and Beth Fletcher, who has accepted the position of MS Walk Committee Chair for 2008. Each of these individuals offered their own unique talents and contributions in supporting the MS Walk.

Harmons MS Bike Tour coming up June 22-24, 2007

The 21st Annual Harmons MS Bike Tour is just days away, and we are anticipating almost 3,000 registered riders! Please join us the weekend of June 22-24 at the Cache County Fairgrounds in Logan for Utah's largest organized, twoday, fully catered bike tour. Not only is this the largest tour in the state, it has the name of being the only bike

tour where you can actually gain weight! Utah's Harmons MS Bike Tour, one of 100 MS Bike Tours across the nation, has a reputation for being the most organized,

As of the print date the MS Walk has received approximately \$413,140 in donations from sponsors and donors... and contributions are still coming in! We thank everyone that has contributed. Did you know that you can continue to make donations and fundraise? Our goal for the MS Walk is \$508,000. You can continue to make donations online at www.fightmsutah.org, click on the MS Walk or mail donations to our office with a reference that your donation is for the MS Walk. Please help us make our goal. Ask if your company offers a matching gift program to match your previous donation. It's a great way to increase your gift.

Again, thank you to everyone that participated, in any way, to the success of the 2007 MS Walk - each person made a commitment to "Join the Movement!"

enjoyable, well fed tour around. It also raises the most money of all fundraising events at the Utah State Chapter, collecting an incredible \$1.3 million dollars at the 2006 event - over 50% of the entire annual

budget for the Chapter.

The Harmons MS Bike Tour is a ride, not a race, and is open to those seven years and older, plus all ability levels. Each rider must pay the registration fee, plus turn in at least \$200 in contributions to the

National MS Society in order to ride. With the great online fundraising tools available

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TEAM MS

Harmons MS Bike Tour

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upon registration, the \$200 is easy to reach. The average rider raised at least \$465 in 2006. Starting with \$500 or more, riders are eligible for commemorative MS Bike Tour cycling jerseys and gift certificates.

The Tour takes place on June 23-24, and riders can select either a 40, 75 or 100 mile route on Saturday, and a 40 or 75 mile route on Sunday. You are free to ride as much or as little as you'd like, and can ride either or both days. Home base for the weekend is the Cache County Fairgrounds, located at 400 S. 500 W., Logan, where camping is free, and plentiful. Families start arriving as early as Thursday to save the best camping spots, and to get ready to enjoy a great weekend for all involved, riding or not.

The route travels through beautiful Cache Valley, offering themed rest stops about every 15 miles, complete with water and sports drinks, and plenty of high carb snacks to keep you going. Bike mechanics, Ride Marshals (EMT), and SAG (safety, assistance, gear) vehicles travel the route to take care of any issues you might have along the route.

To participate, please visit our Web site at <u>www.fightmsutah.org</u> or contact Rachel Taylor at <u>rachel.taylor@nmss.org</u>.

The 2007 Harmons MS Bike Tour starts June 22 at the Cache Valley Fairgrounds in Logan, UTAH. THIS IS THE BIG ONE! Join us for the most fun event in the STATE.

We need volunteers for registration, facilities maintenance, volunteer hospitality, start & finish line cheerleaders, wandering "Ask Me" agents, and much, much more!

We can accommodate a volunteer position with your skills, time, and interests.

Volunteer opportunities start June 22 and run through June 24.

We have opportunities that begin early in the morning and others that begin in the afternoon and evening. So, no matter what your schedule is, we'd love to have your help.

You can get involved by registering online at <u>www.fightmsutah.org</u> or contact Brandon Hill at 801-424-0113, press option 2, ext. 116 or <u>brandon.</u> <u>hill@nmss.org</u>



WAYS TO GIVE

SAFE AND EASY: GIVE ONLINE

"The Internet is a tremendous tool to help people join the MS movement," said Joyce Nelson, President and CEO of the Society. "We hope to cut administrative costs, make giving easier, and better tailor information to suit our constituents' interests."

"Tremendous" is no exaggeration:

According to a USA Today report, online donations to the nation's biggest nonprofit organizations increased 63% from 2003 to 2005. The Society has led the way on the Web since 2001 when we first made it possible to sponsor Bike and Walk participants online.

To pledge online, go to

nationalmssociety.org and click on the heart-shaped button ("Pledge/Sponsor a Participant"). Then use the search engine to find the person or the team you'd like to sponsor.

New online opportunities

The Society recently expanded its Web site to make it easy to give in other ways. At <u>nationalmssociety.org</u>, click on the gift-box shaped button ("Donate to the Society") to access the Donate page. Visitors may choose:

Donate Now, to safely and securely give a one-time gift to the Society. You can also search to see if your employer is one of the many companies that will match an online gift with a contribution of their own.

Tributes and Memorials, to create a personal page to honor a loved one, to give a one-time contribution, or to set up

an automatic annual or monthly tribute or memorial gift.

Workplace Giving, where you may sign up to have a regular payroll deduction dedicated to the MS movement. The payment is sent to us automatically.

Planned Giving, to learn about other ways to support the Society through a will, gift annuities, charitable trusts, and more.

A SPARKLING WAY TO GIVE

Check out the new line of jewelry at Christopher & Banks and CJ Banks stores. There are nearly 750 stores nationwide—and this May and June they are offering the sparkling new "MS Collection."

The moderately priced earrings, necklace, and bracelet are created with genuine Swarovski crystals—and the National MS Society will receive 50% of the proceeds. Just in time for graduations, weddings, Challenge Walks, and other special summer events. For store locations, go to <u>www.christopherandbanks.com</u>.

COOL TIPS FOR HOT DAYS

Pre-cool

"Pre-cooling" may lessen the heating effects of strenuous activity. Submerge in a tub of cool water for optimal benefit. Use mint soap for a cool skin sensation.

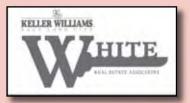
For information on heat sensitivity, go to <u>nationalmssociety.org/sourcebook.</u> Click on heat/temperature.



3rd Party Fundraisers

Thank you to all of our spring 3rd Party Fundraisers!

Current 3rd Party Events...



Throughout 2007, the White Real-Estate Associates at Keller Williams will donate a portion from each sale to the National MS Society Utah State Chapter.

Other spring 3rd Party Fundraisers...

- Fraternal Order of Eagles, Utah State REAC
- Association of Government Accountants

Host your own 3rd Party Fundraiser. It's easy, fun, and for a good cause!

For more information on how to host your own 3rd Party Fundraiser, contact Brandon Hill at 801-424-0113, option 2 or <u>brandon.hill@nmss.org.</u>

Living Well with MS: A Workshop Series

Have you ever thought, "I never expected my life this way. How do I deal with my feelings, discuss needs with my family, or handle looking well but feeling sick"?

The Utah State Chapter is collaborating with **LIVING WELL**, **LLC***, to provide a new program, **Living Well with MS** to address the challenges of MS. The program will include monthly workshops addressing many issues. The first session is mandatory.

Workshop Dates and Topics

- July 10 MS: What Can I Do?
- TBD Managing Stress
- TBD Pacing and Fatigue
- TBD Emotional Intelligence
- TBD Social Support
- TBD Pain Management
- TBD Sleep Habits

*LIVING WELL is a health psychology center that specializes in helping people learn to live well with chronic illness.

All sessions will be from 6:00-8:00 p.m. and held at the Utah State Chapter office. You can register by calling 801-424-0113, press option 2 or e-mail Clare at <u>clare.wright@nmss.org</u>.

Visit <u>www.fighmsutah.org</u> or check your mail box soon for more details.

Memorials

Edward White Earline Holley

Eva Newsom

Social Security Administration Phyllis & Lee King

Colleen Pearson Mr. & Mrs. Richard Coleman

Dr. Mach Clayton

Dr. & Mrs. Charles Behrens

Morris Howell

Curt & Stacy Howell

Ronald Bodell

George & Gerry Wilberger Stephen & Paulette Camden

Gladys Pilon

Geraldine & Jay Eugster

Kyle McQuarrie Dr. & Mrs. Charles Behrens

Robert Byerline

Dr. & Mrs. Charles Behrens

Tributes

Olivia Lee

Mr. & Mrs. George Robinson Wayne Lee DeeAnn Benson Lindsey Smith Kay & Joe Stevenson L.B. & G.K. Evans Estefania Sadler Dean & Ruth Lee

The Chapter wishes to thank the many generous donors who have made memorials and tributes in 2007. For more information on the Tributes and Memorials Program, contact Kim Gallegos at the Chapter by calling 801-424-0113, select option 2 or e-mail <u>kim.gallegos@nmss.org</u>. For information on leaving a bequest in your will, contact our Gifts Office 800-923-7727.

千 TRIBUTES & MEMORIALS 🚗

In lieu of gifts for special events, or flowers for a funeral, many people choose to make a tribute in honor of a loved one. This form has been included for your convenience. If you prefer to make a donation by phone please call 801-424-0113, select option 2.

In Honor of:

Would you like your gift recorded as a: Memorial Gift (deceased honoree)Tribute (living honoree)
Donor's Name:
Address:
City, State, Zip:
Phone:e mail:
Donation Amount:\$ Payment Type: Check Credit
Card Type: AMEX VISA MC Number:
Security Code: Expiration:
To Whom Should We Send Notification of Your Gift: Name:
Address:
City, State, Zip:
Would You Like Us To Disclose Your Gift Amount: Yes No



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Multiple Sclerosis

First questions. Then answers.

A trusted resource for people newly diagnosed with MS

Have you recently been diagnosed with multiple sclerosis (MS)? What are your *first questions*? Who can you ask? Are you not even sure where to begin?

A neurologist or other MS specialist is available to discuss common questions about MS. This is your chance to ask, listen, and learn.

The teleconference is held on the first Tuesday and the third Tuesday of each month. Be sure to check the reverse side of this card for the start time from your calling area. No preregistration is required.



You may be feeling overwhelmed, but you're not alone. Get the information you need now.

To join the call, dial 1.877.748.8211 ten minutes before the start time on the first or third Tuesday of the month. When asked for a code, please say "MS teleconference." If you need additional information or would like to view optional slides for the program, please visit www.MSActiveSource.com.

This teleconference is sponsored by Biogen Idec.

Multiple Sclerosis

First questions. Then answers.

A trusted resource for people newly diagnosed with MS

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
		First Tuesday	/			
		Third Tuesday	,			

Available from July 17, 2007 to November 6, 2007.

To join the call, dial 1.877.748.8211 ten minutes before the start time on the first or third Tuesday of the month. When asked for a code, please say "MS teleconference."

Below please find the start time for your calling area:

First Tuesday 7 PM Eastern Time 6 PM Central Time 5 PM Mountain Time 4 PM Pacific Time Third Tuesday 10 PM Eastern Time 9 PM Central Time 8 PM Mountain Time 7 PM Pacific Time

For more information about this teleconference, please visit www.MSActiveSource.com.

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NATIONAL **Multiple Sclerosis** Society

Utah State Chapter

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