

chapter news	3-5	discovery circle	13-16
research	6	memorials & tributes	15-16
team talk	8-11	knowledge/programs	16-26
advocacy	12	self help groups	27

msconnection

Utah State Chapter

Eastmont Middle School Raised Over \$7,000 to Fight MS

By Jessica Knickerbocker, Volunteer Associate

Eastmont Middle School, located in Sandy, held a fundraiser for the National MS Society Utah State Chapter in December. The students wanted to honor Mrs. Diane Florez, their school counselor, who was diagnosed with MS in 1975.

The student body officers held a wonderful assembly on November 30 to kick-off the students' fund raising efforts. They surprised Mrs. Florez by having her husband and children there, and by putting together a slideshow of family and school photos. Andrea White, Ph.D., gave a presentation about MS to an outstanding, attentive audience. The assembly ended with teacher Cindy



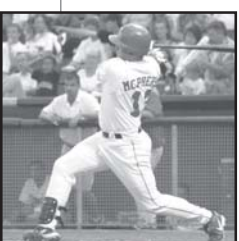
Cindy Benton and the student body officers dye Principal Ann White's hair pink!

Benton and Principal Ann White promising to dye their hair pink for a week if the students raised a certain amount of money.

True to their word, Mrs. Benton and Mrs. White had pink hair on December 14 when they announced that the students of Eastmont had raised \$7,683! Mrs. Florez entered the auditorium that morning to a standing ovation. She refers

continued on page 5

*Tysabri
Breaking
News,
Page 22*



Tami Featherstone, Diane Florez and Courtney Garay



Ask the Neurologist

SERIES 2005

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 pm Arrival and Dinner at the Ramada • 2455 S. State • SLC, Utah
- 6:30 - 6:40 pm Brief Presentation-Teva Neuroscience
- 6:40 - 6:50 pm Late breaking information-MS Specialist
- 6:50 - 7:40 pm YOUR QUESTIONS to the Neurologist

This will be a complimentary program with dinner snack provided.
Please RSVP to: 1-866-227-9788 Ext. 4208. Please state which programs you will be attending along with your name and phone.
Seating will be limited and taken on a first come, first serve basis.

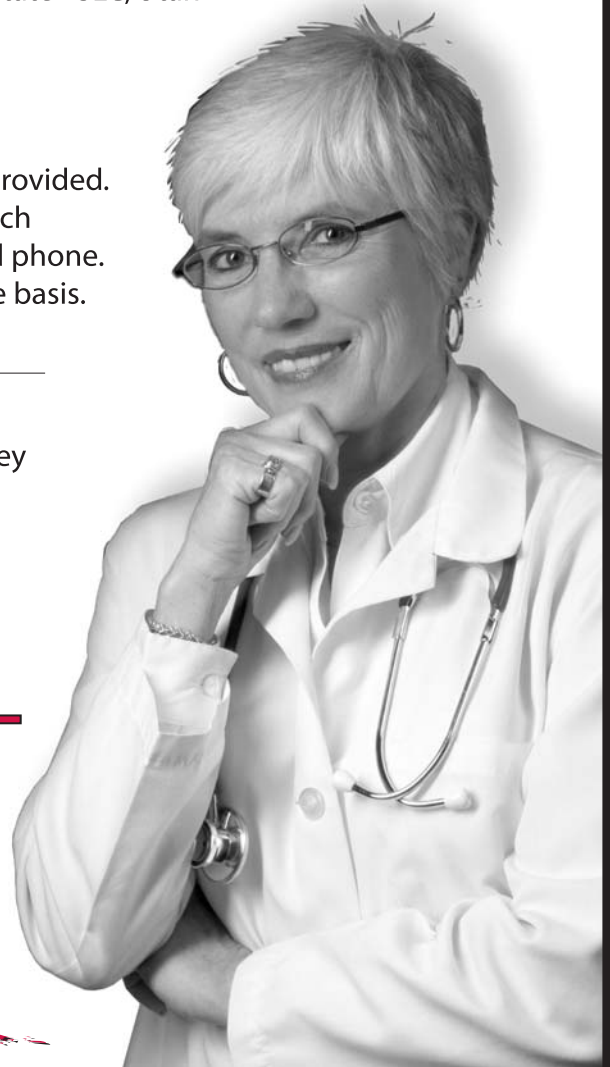
Dates:

- | | |
|----------------------------|----------------------|
| Tues. - January 25, 2005 | Dr. John Rose |
| Tues. - February 22, 2005 | Dr. Patrice Duverney |
| Tues. - March 22, 2005 | Dr. John Steffens |
| Tues. - April 26, 2005 | Dr. Evan Black |
| Tues. - August 30, 2005 | To be Announced |
| Tues. - September 27, 2005 | Julia Klein, NP |
| Tues. - October 25, 2005 | Dr. John Foley |

Location:

Ramada Inn • 2455 S. State • Salt Lake City
(Enter on the South Side Toward the Rear)

Please Join Us!



The National MS Society Welcomes New Board of Trustees Chair



Jay Gurmankin

The National Multiple Sclerosis Society Utah State Chapter welcomes Jay Gurmankin as its new Board of Trustees Chair. Over the past six years Gurmankin has contributed greatly to the multiple sclerosis community. He has served on the Utah State Chapter Board of Trustees and was the Programs Committee Chair. He has also lent his talents to the MS Walk, Major Gifts, and Dinner of Champions Committees.

In 2002 the Utah State Chapter honored him with the Leadership Volunteer of the Year Award. Gurmankin, an attorney at Holmes, Roberts, and Owen LLP, is an excellent resource for people with MS.

His commitment to helping those with MS goes well beyond the boardroom, as he has donated his time and expertise in pro bono cases helping people with MS.

His many goals for the Utah State Chapter in 2005 include; developing strategic initiatives for establishing new programs, increasing fundraising, expanding the Board of Trustees, having board members participate as volunteers at Society events, and creating resources for children whose parents have MS.

"I am thankful for the talented Board of Trustees and staff at the Utah State Chapter," Gurmankin said. "I look forward to working with them in achieving these goals and furthering the mission of the National Multiple Sclerosis Society."

Publication of the National MS Society Utah State Chapter
2995 South West Temple, Ste. C
Salt Lake City, Utah 84115

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 of 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.

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

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- Index of Advertisers -

Teva Neuroscience	2
Biogen Idec	7
MS Life Lines	28

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6th  Annual

Women Against MS

Champagne Luncheon & Fashion Show

Presented by



The Women Against MS Champagne Luncheon Is Always in Fashion

The Utah State Chapter held the Sixth Annual Women Against MS Champagne Luncheon & Fashion Show on Saturday, February 26 at the Little America Hotel to raise money for MS research and programs. During the luncheon, over 460 attendees learned about multiple sclerosis and enjoyed a spring fashion show presented by local clothing boutique, Great Garb. Because of the generosity of 1-800 CONTACTS, the McCarthy Family, Harris H. and Amanda P. Simmons Foundation, Betaseron, CarePoint Group Purchasing, Dr. and Mrs. Dan Henry, and Vanguard Media Group, 100 percent of the money raised at the event will benefit everyone whose lives are touched by MS.

This year, attendees enjoyed a message of hope from a speaker who knows just how devastating MS really is. Liz Clark, a local Utahn, encouraged attendees to live their dreams by actively fighting MS; Robert Fujinami, Ph.D., a neurologist at the University of Utah, gave an informative update on the latest MS research findings and Promise 2010. Each speaker sent a special message that proved that everyone in our community plays an integral part in the fight against MS.

To conclude the afternoon, Great Garb presented an incredible fashion show highlighting Spring 2005

continued on following page

CHAPTER NEWS

fashions from designers like Theory, Leona Edmiston, and Isabella De Pedro.

Mark your calendars for next year's Champagne Luncheon and Fashion Show, which will be held Saturday, February 25, 2006.

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. Philip McCarthy, Chair; Betsy Hunt, Co-chair; Kelli Fratto Bland; Clara Brennan; Debbie Don; Anne Harte; Diane Henry; Hope Hooton; Maybell McCann; Melisa Mitchell; Wendy Park; and Ann Sasich for working long hours to ensure that WAMS was a terrific success.

This year's event had outstanding support from generous sponsors: 1-800 CONTACTS, the McCarthy Family, Harris H. and Amanda P. Simmons Foundation, Betaseron, CarePoint Group Purchasing, Dr. and Mrs. Dan Henry, and Vanguard Media Group. And we couldn't have done it without our in-kind sponsors Beautifully Done Events, Bellezza, Trent Call, Fox 13, Great Garb, LTS Leadership Board of Salt Lake, Little America Hotel, The McCune Mansion, and Roots, Inc. flowershop.

■ Eastmont Middle School Raised Over \$7,000 to Fight MS

— *continued from page 1*

to her co-workers and the student body as "a 1,000 person support system."

Mrs. Florez has always been impressed with the way her students have reached out a helping hand, saying, "they open doors I don't need to go through." She does admit, however, that this fundraising experience has helped open her students' eyes to the affects of MS, and "they've reached out even more since the assemblies."

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Researchers Find Clue to Why Women Get MS More Often Than Men

An international team of researchers funded in part by the National MS Society has uncovered a genetic clue which, if confirmed, may help explain why women develop MS about twice as often as men. The report, from collaborators in Minnesota, Northern Ireland, Belgium and Italy, appears in the Jan. 27 online publication of the journal *Genes & Immunity*.

It is known that genes play a part in making people susceptible to developing multiple sclerosis. There appear to be many separate genes that contribute to susceptibility. The international team, headed by Brian Weinshenker, MD (Mayo Clinic, Rochester, MN) has identified a variation in a gene that controls a powerful immune messenger chemical called interferon (IFN) gamma.

Unlike interferon betas, which are used to treat MS, IFN gamma has been linked to immune attacks in MS, and recent evidence suggests that it is more active in women who have MS than in men.

The team compared MS in different U.S. and European populations. Their

preliminary findings suggest that men have the gene variant that causes high levels of interferon gamma less often than women. This may explain why fewer men have MS than women. Dr. Weinshenker explains, "...Interferon gamma...appears to be a new key variable in understanding who gets MS and who doesn't, and especially why women develop MS more often than men. If you have a gene that produces high levels of interferon gamma, it may predispose you to developing MS."



The genetic variation identified by this international team may be just one piece of a

complex puzzle. This finding, if confirmed, provides a possible target for further investigation into what causes MS and how to stop the immune-mediated disease.

This project was funded through collaborative funding between the National MS Society and the NIH's National Institute of Allergy and Infectious Disease to foster the study of the influence of gender on immune responses. This collaboration was part of the Society's targeted initiative to study gender differences in MS.



Where you'll find **ANSWERS.** *Straight from the Heart.*

MS ActiveSourceSM ●●● a source of information and services for the entire multiple sclerosis (MS) community.

MS ActiveSource is a comprehensive source of information and services for the entire multiple sclerosis (MS) community. This service, sponsored by Biogen Idec and Elan, provides the latest information on MS and MS treatments through a variety of sources. No matter how you wish to reach us we are available to assist you with reimbursement related issues, therapy administration training, infusion support, general MS information, and much more.

MS ActiveSource provides a variety of programs and services.

Some of these include:

- A call center staffed by highly trained MS Support Specialists ready to answer your MS related questions, including reimbursement related issues, therapy administration, infusion support, and general MS information
- An array of live local events and educational teleconferences that focus on the issues that matter to you most
- MSActiveSource.com, one of the largest MS resources on the Internet, can be accessed 24 hours a day



www.MSActiveSource.com

MS ActiveSourceSM
Take an Active Role

You're invited to ask questions at two highly-informative MS events

Here's your chance to make important discoveries regarding the latest Multiple Sclerosis (MS) advances. Come to one or both of these free live programs and hear the insight of an MS healthcare expert. Get your questions answered. What you learn can make a difference!

Wednesday, April 20, 2005

Registration: 6:00 PM

Program: 7:00 PM

Location:

Marriott Hotel
101 West 100 North
Provo, UT 84601

Christopher J. Reynolds, MD
Neurological Associates

Mohammad Entezari-Taher, MD
Neurological Associates

Tuesday, April 26, 2005

Registration: 6:00 PM

Program: 7:00 PM

Location:

Hilton Salt Lake City Center
255 South West Temple
Salt Lake City, UT 84101

John Foley, MD
Rocky Mountain MS Clinic

To register for one or both of these free programs, call 1-866-955-9999 or visit our website www.MSActiveSource.com/events

MS ActiveSource is a service mark of Biogen Idec.
MS ActiveSource is sponsored by Biogen Idec and Elan.



Walk All Over MS at the MS Walk Around the World

Put on your walking shoes because the 16th Annual MS Walk is right around the corner. The popular fundraiser will be held statewide in St. George (March 26), Ogden, Provo, Salt Lake City, Vernal (April 9), and Cedar City (April 23). The MS Walk 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 4-6-mile routes, which are wheelchair accessible. Money raised from the event will further MS research projects and local programs which help people affected by MS. In 2004, statewide, over 1,600 people participated in the MS Walk, which raised over \$289,000! The Utah State Chapter hopes to raise \$300,000 from the 2005 MS Walk.

This year the National MS Society will celebrate cultural diversity with the theme, "MS Walk Around the World." Participants are encouraged to come in traditional dress representing cultures and countries from around the world.

To register or volunteer for the MS Walk visit www.fightmsutah.org, or call the Utah

State Chapter at 800-527-8116.

Registration brochures are available at the customer service booth/Business Center at all Harmons, your neighborhood grocer®.

Participants will also be available to register the morning of the event, however, it is recommended to register in advance to avoid long lines on the day of the event.

When and Where to Walk

<u>Location</u>	<u>Date and Time</u>
St. George	March 26
Christensen Park	9:30 a.m.
Ogden	April 9
Lorin Farr Park	9:30 a.m.
Provo	April 9
Exchange Park	9:30 a.m.
Salt Lake City	April 9
Utah Cultural Celeb. Cent. .	9:30 a.m.
Vernal	April 9
Searle Pavilion	9:30 a.m.
Cedar City	April 23
Providence Center	10:00 a.m.

Fundraising Tips for the MS Walk

Don't wait until the last minute to start fundraising for the MS Walk. The National MS Society Utah State Chapter offers several useful online tools for individual and team fundraising.

The tools are easy to use and make fundraising simple and fun. Even those without extensive computer knowledge can

create their own Web page in under 15 minutes with easy to follow, step by step instructions.

Once you register online, simply click on "my account," to view the online tools. Individual and team tools include; a pledge

continued on following page

■ Fundraising Tips for the MS Walk

— *continued from previous page*

report (lists your sponsors and pledges for the event), personal Web page (create your own page featuring photos and an inspiring story, telling everyone why you are walking), sponsor me email (send email messages to family and friends to sponsor you), and an email tracking report (keeps track of the people you have sent "sponsor me" e-mails to any pledges they made).

Tools specific to teams include; team Web page (team captains can design a homepage for their team including a photo, logo, and team story), join my team email (send email messages to friends and family inviting them to join your team), team

roster (view the registered members for your team), contact team email (send email messages to your team), and manage my team (send a request to your chapter to add or drop team members).

Other online tools include great examples and ideas for letter writing campaigns, flyers, and fundraising kits. Don't be afraid to get creative. It's often the most imaginative ideas that raise the most money.

So get online and have some fun raising money for the MS Walk. Visit the Utah State Chapter's Web site at www.fightmsutah.org.

msClassic

Take a Swing at MS

World class golf at one of the world's most exhilarating courses.
1-800 FIGHT MS
www.fightmsutah.org

Thursday, June 2
Promontory - The Ranch Club

2004 MS WALK - TOP 20 FUNDRAISERS

<u>NAME</u>	<u>TEAM NAME</u>	<u>TOTAL RAISED</u>
Christa Aquilla	Team Goldman Sachs	\$12,228
Clifta Corless	Team The Mayor's Own	\$4,005
Sharon Kerkman		\$3,890
Katie Hill	Team Boies	\$3,230
Courtney Johnson	Team Camelback Crew	\$3,075
Hank Schnaubelt	Team Red Mountain Treckers	\$3,045
Dawn Silcox	Team Snoopy	\$2,670
Troy Passey	Team Lightning Bolts	\$2,600
Denise Hadley		\$2,585
Shirley Angel	Team The Chocoholics	\$2,550
Heather Boies	Team Boies	\$2,235
Milton Katsikathas	Team Tankers	\$1,830
Sharon Oveson	Team S.O.S.	\$1,638
Jean Anderson	Team Lightning Bolts	\$1,592
Gina Anderson	Team Lainas Courage	\$1,450
Vernie. Heeney	Team The Mayor's Own	\$1,405
Linda Stallings	Team Linda's Lifesaver's	\$1,404
Crystal Coleman	Team Westminster	\$1,330
Dahn Caldwell		\$1,285
Terry Fletcher	Team SPIRIT	\$1,264

"As we're approaching the 2005 MS Walk, we'd like to thank last year's top fundraisers for the outstanding job they did, and look forward to seeing them walk all over MS in 2005."

MS Band of Hope

The National MS Society encourages you to show your love of a family member or friend with MS, by purchasing the new MS Band of Hope. The MS Band of Hope is a great way to show the world that you are committed to the fight against MS. The band is an excellent tool for teams that participate in the MS Walk or MS 150 Bike Tour to show that they are united to the cause. Proceeds from the band will go to further MS research and local programs that benefit Utahns and their families, moving us one step closer to the day when MS stands for, mystery solved!

The wristbands are available in adult and youth sizes and are sold in groups of 10 for \$10, plus shipping if applicable. To place your order, call 1-800 FIGHT MS.



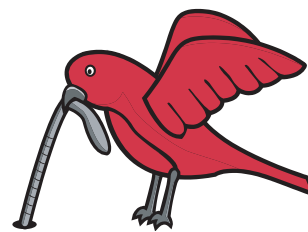
MS 150 Bike Tour Early Bird Registration Ends March 31!

Participants who take advantage of the early bird registration for Utah's 19th Annual MS 150 Bike Tour by registering by Thursday, March 31, will receive the discounted registration rate of \$30 per person. Regular registration is \$40 and late registration, after June 1, is \$50. There is a \$5 discount for registering online at www.fightmsutah.org.

Nearly 1,800 cyclists are expected to ride in the 2005 MS 150 Bike Tour, which will take place along scenic roads in Cache Valley, Saturday, June 25 and Sunday, June 26. The yearly fundraiser supports nationally-funded research, client programs, professional education, and is the largest organized two-day cycling event in Utah.

The ride begins early Saturday morning with a sea of cyclists gathered at the start line looking sharp in their team's individually designed jerseys. It doesn't matter if participants are beginning riders or if they're Lance Armstrong, cyclists of all abilities ride 40, 75, 100, or 150 miles during the fully-catered, two-day tour that begins and ends each day at the Cache County Fairgrounds.

Riders will have access to rest stops; food and water; first-aid support; and safety, assist, and gear (SAG) wagons along the route. Saturday night, riders and their families will enjoy a pool party and an awards dinner presentation with Bill Allred of X96.



Last year over 1,600 Utahns participated in the event, which raised \$805,352, with an average fundraising contribution of \$389 per rider. Participants are required to submit a minimum of \$200 in contributions from family, friends, and co-workers in order to ride.

Registration brochures for the MS 150 Bike Tour 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 or call the Utah State Chapter at 801-493-0113. Registration will also be available at the event, but it is recommended to register in advance to avoid long lines.

CALLING ALL VOLUNTEERS!

The MS 150 Bike Tour is June 25-26 in Cache Valley and we need your help!

**Have car?
Will drive cyclists?
We need SAG Drivers**
(Safety, Assistance, & Gear)
to drive the route and
help riders in need.
Call us for more info.



**We have lots of one-
and two-day volunteer
opportunities available!**
Please visit
www.fightmsutah.org
or call 493-0113 and ask
for Jessica Knickerbocker

MS Advocacy: 2005 Political Outlook

The effort to curb federal spending, along with the increasing cost of war, counter-terrorism measures and health care, could threaten programs of great importance to the MS community. MS Advocates play an especially critical role in the current political environment.

Following the swearing-in of President Bush, federal legislators are back in Washington and ready to begin the major work of the 109th Congress.

With Republican majorities in the House and Senate, many lawmakers are expected to support the President's key goals, such as cutting the deficit in half by the end of FY'09.

Our inaugural Federal Focus seeks to provide advocates with quick information on issues of importance to the Society's 2005 federal advocacy efforts, including biomedical research and health coverage for people with multiple sclerosis, along with details and links to more in-depth resources and policy analysis.

Will Medicaid Reform Hurt Those Most In Need?

Medicaid reform should be a dominant issue facing Congress this year. The major concern over reform is that any effort to block grant federal funding to the states will result in fewer federal dollars and decreased overall Medicaid funding. This could result in both a reduction in

coverage and a reduction of the number of people eligible for Medicaid benefits. Although the Medicaid program covers only 5-10% of people with MS, these individuals tend to be those with more progressive MS and those most in need of medical coverage.

With the aim of protecting benefits for people receiving health coverage under Medicaid, the Society has joined numerous patient advocacy organizations and other groups in opposing federal cuts or funding caps.

The White House outlined its plan for changes to Medicaid in its FY'06 budget plan on February 7th. We will monitor all reform proposals with the intent of opposing cuts that result in decreased services.



Make Your Voice Heard! Join the MS Action Network.

Join the National MS Society's advocacy efforts to maximize your impact on public policy issues affecting individuals with multiple sclerosis. MS Action Network members receive via e-mail all legislative alerts and federal and state updates. Sign up today at www.nationalmssociety.org — You can make a difference.



Workplace Giving

EVERYTHING SHOULD BE THIS SIMPLE.

Workplace Giving programs are a convenient, easy way for you to contribute to the fight against MS. You just designate the amount you'd like to contribute on an annual basis. Your donation is then automatically deducted from each paycheck and sent directly to the National MS Society.

In most public and private workplace giving campaigns, you will find the National MS Society listed under 'Community Health Charities.' If you work in the public sector or you're in the military, donations can be made through the Combined Federal Campaign (CFC) by selecting code number 0549. If you work in the private sector, talk to your benefits administrator about contributing through your company's Workplace Giving program.

Workplace Giving: helping in the fight against MS has never been easier.



Designate the National MS Society
CFC #0549

Your Footprints

Everyone leaves footprints on the sands of time. A person is remembered for the weight of his or her character

- For indentations of accomplishment;
- For shapes of kindness;
- For length of compassion;
- For width of personal warmth;
- For generosity;
- For values.

When we leave positive impressions behind, we enhance the lives of our friends and loved ones. We give them footprints to follow.

Thoughtful estate planning is one means we have to make a print in the sand to help others recall our priorities. For example, consider the effect of even a simple will or trust that includes provision for family members and resources for the charitable causes you support, like the National Multiple Sclerosis Society.

An estate gift makes a positive statement.

When you include the Society in the final disposition of your estate, you declare to your family and friends that you believe in and care about our mission. Your parting gift becomes a clear declaration of your values.

An estate gift provides needed funding.

Estate gifts are especially valuable, not only

because they tend to be larger than annual gifts, but also because they often come at critical times.

They provide that extra boost to the budget that can make the difference between research and program advancement and retrenchment.



Estate gifts can be designated for a specific purpose such as a local program, research or college scholarships, or they can be unrestricted for use where needed most.

An estate gift encourages imitation. There's something about a well-planned estate gift that influences others to "go and do likewise."

As friends and family members plan their own estates, they may recall your generosity and thoughtfulness. Your gift may unlock resources from other estates that help us to end the devastating effects of MS.

Dedicated staff is available to provide you with the information and materials you need to include charitable giving in your overall estate plan.

To request a complimentary brochure entitled "Creating A Legacy for Tomorrow," contact the Gift Planning office at 1-800-923-7727, or visit our Web site at nationalmssociety.org and click on the "Donate" button and then explore the "Guide to Giving" section.

Community Partners in Hope

The following partners contribute to our mission by giving to many vital Utah State Chapter activities. We appreciate their generosity. To find out how to become a *Community Partner in Hope*, call Courtney at 801-493-0113.

AVONEX[®]
(Interferon beta-1a)
IM Injection

BETASERON[®]
[INTERFERON BETA-1b]
FOR SC INJECTION

HARMONS
your neighborhood grocer

The
McCarthy
Family

 **Rebif**[®]
(interferon beta-1a)
sc injection

TEVA[®]
NEUROSCIENCE

MEMORIALS & TRIBUTES

IN MEMORY OF

Carolyn "Kelly"

Clements Griffiths

By Beverly Smith
Colene Clouse

Christine Adair Lytton

By Maggie Kearns
Cuong Tran

Pamela Laishley

Darlene Jemmings

Doris Beckwith

By Barbara Crouch

John Peter Brown

By Linda Danielson
Donna Davies

Leo Sotiriou

Maxine Babalis

Korey Searcy

By Kristin Searcy
Jolene Fulmer

Joanne Kelly

Annette Koga

Toni Koga

Lynn Summers

By Rex Sonnenfelt
Gretchen Price

Mary Matsushima

Charlotte Campbell

La Var Stark

Lavon Chard

Rose Meier Howe

By DeAnn Rasmussen

Thomas Gordon

By Clara Contratto
Vivian Gordon

Marsha Moeller

Mary Anderson

Will Allison

By Carol Stavrakakis

The Memorials and Tributes contribution form is located on the following page.

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.

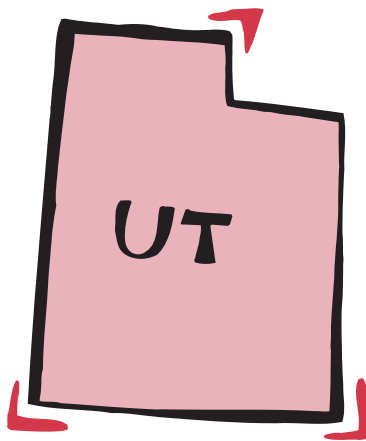


KNOWLEDGE/PROGRAMS

Educational Seminar to Travel the State

"The Path Back from an MS Attack," an educational seminar, has been traveling around the state this month. So far chapter staff have visited St. George, Cedar City, Salt Lake, and Ogden. We will be in Price on March 19 and Provo on March 22. If you would like to participate in Price or Provo, call the chapter today!

The information used for this program is from the North American Education Conference where a different topic is selected each year. This year, the topic was rehabilitation. At each



location the Utah State Chapter visited, a local professional was there to give suggestions, tips, and helpful hints on rehabilitation with MS.

A short video talking with rehabilitation professionals from across the US was shown. Each participant was also given a supplemental 128-page booklet, which offers additional in-depth research information. If you

missed this program but would like to view the video or receive a booklet, please contact the chapter at 800-527-8116.

MS 101: Newly Diagnosed Forum

Are you newly diagnosed with questions about MS? Have you had MS for a while and still have questions? Want to learn more about the Utah State Chapter? If so, MS 101 is for you!

April 14 - Julie Klein, NP
 June 1 - Kara Menning, NP
 August 3 - Emily Griffin

The Forum will begin at 12:00 noon
 Utah State Chapter
 2995 S. West Temple, Suite C, SLC

Lunch will be provided by Avonex, Betaseron, Rebif, and Teva Neuroscience.

Contact the chapter if you are planning to attend. You can do so by calling 801-493-0113. Seating is limited. Come with questions and an empty stomach!

Men's Night Out:

Sex, Sports, & Shots

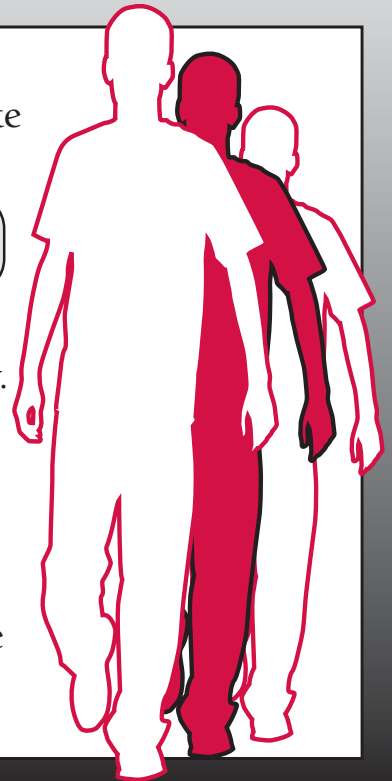
Did you know that men experience MS symptoms differently than women? This is why the Utah State Chapter is holding a program for men with MS.

Date: April 19, 2005 • **Time:** 6:30 - 9:00 p.m.
Location: Wilkinson Auditorium at Cottonwood Hospital

This program will address:

Sex - A Urologist will speak on how MS affects sexuality.
Sports - Learn from a Physical Therapist with an MS specialty how to enhance your physical activity.
Shots - Doctors John Rose and John Foley will be on a panel to answer questions about medications and MS.

This exclusive program is for men only; questions are encouraged and dinner will be served. To register, call the chapter today at 801-493-0113 or visit us online at www.fightmsutah.org.



Urine Control for Individuals with MS

Urine control is often a challenge for people with multiple sclerosis. For some individuals, MS affects urinary function. For others, limited mobility makes getting to a restroom in time a significant challenge.

For people with MS, bladder related problems include:

- Frequency, the urge to urinate frequently
- Retention, the inability to completely drain the bladder
- Free flow, the inability to hold urine
- Functional incontinence, the inability to reach a restroom in time once you have gotten the signal

The primary goal of health care professionals treating MS patients is to preserve proper bladder function. It is important that a person experiencing urinary problems have a thorough evaluation by a urologist to exclude causes of bladder dysfunction other than MS, and to diagnose whether the problem is failure to store or failure to empty.

The most common method of dealing with urinary problems is the use of anticholinergic and other drugs for bladder control (Ditropan, Detrol, etc.) Surgery, exercise and diet are often beneficial in restoring bladder function as well.

When proper urinary function cannot be preserved, a continence management product may be necessary. Many methods of bladder management exist, including

recent innovations designed to help keep people dry, secure and active.

Adult diapers/absorbent briefs and pads

Adult diapers or absorbent briefs are a temporary option for individuals who experience incontinence. They are available in multiple sizes and capacities to meet the individual's amount of urine loss. Adult diapers hold significant amounts of liquid. However, moisture held against the skin can be uncomfortable and may result in skin breakdown with problems such as rashes or infections. Diapers are not recommended for individuals who use wheelchairs due to the potential for pressure sores.

Adjunct products, such as wipes and skin-care products may help to reduce diaper complications. Many brands of adult diapers are available.

Foley Catheters

The Foley catheter, or indwelling catheter, is an aseptic tube inserted through the urinary opening and into the bladder to drain urine. Indwelling catheters are held in place by an attached balloon, inflated in the bladder.

Although Foley catheters are inexpensive and convenient due to their extended wear time, prolonged use of Foley catheters for the management of urinary incontinence can be dangerous. Foley catheter use results in a high incidence of infection. Infection-causing bacteria can be introduced into the urinary tract and

continued on following page

■ Urine Control for Individuals with MS

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bladder by an indwelling catheter. Foley catheter users must closely monitor their catheter use for signs of infection.

Suprapubic Catheters

A suprapubic catheter is a permanent device inserted into the bladder through a surgical incision in the abdominal wall by a urologist during an outpatient surgery or office procedure. These catheters drain into standard urine collection bags.

Suprapubic catheters need to be closely monitored by a healthcare professional, such as a urologist to avoid complications such as bladder or kidney infection, catheter site leakage, skin breakdown or blood in the urine (hematuria).

Condom Catheters

Condom catheters are a method of urine control for men. Also known as penile

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• BROCHURE HIGHLIGHT •

Controlling Bladder Problems in Multiple Sclerosis

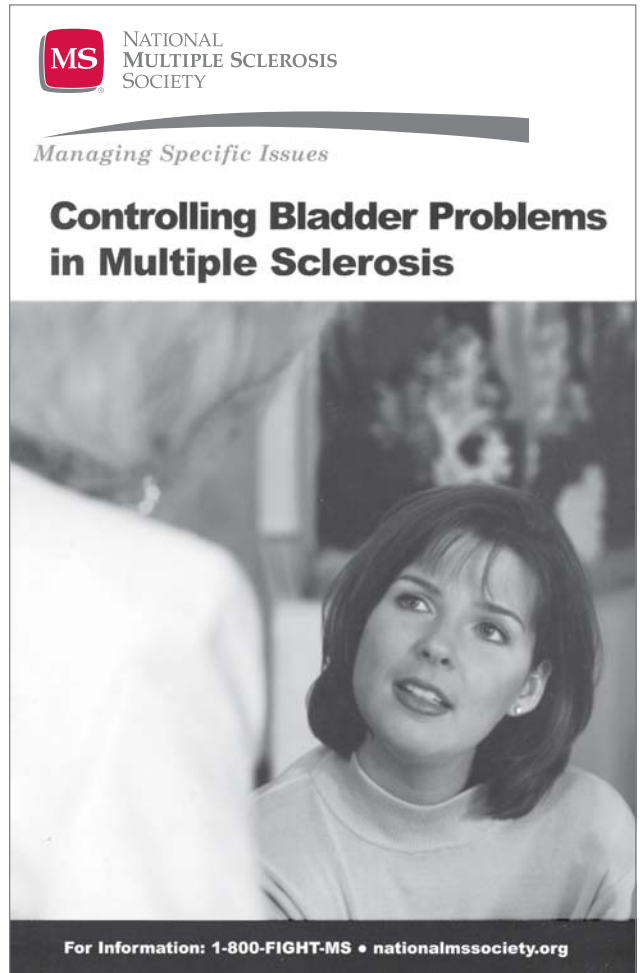
Written by Registered Nurse and Vice President of the Professional Resource Center, Nancy J. Holland, RN, EdD, this 20-page brochure explains how MS may affect the urinary system and what can be done to keep problems under control.

The brochure states that the goals of bladder management are:

- To preserve normal urinary tract function and prevent potentially dangerous complications.
- To relieve symptoms.

It also explains how the bladder functions, how MS can disrupt the system, and ways to manage potential problems.

To obtain a copy of this brochure, or to get information on other brochures available from the National MS Society, please contact the chapter at 801-493-0113.



■ Urine Control for Individuals with MS

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sheaths or Texas catheters, these products are rolled over the penis like a condom. An opening at the tip connects to a urine drainage tube that leads to a collection bag, usually a small leg bag. Adhesives are applied to the inner surface of many condom catheters to attach the device to the penile shaft. Other condom catheters use a strap made of foam, rubber or adhesive materials that wrap around the condom and penile shaft to hold the condom in place. Condom catheter users should be careful and consult with their doctor to avoid complications such as rashes, wounds or skin irritations that can arise from repeated application and removal. Condom catheter use can also lead to urinary-tract infections.

External Continence Device for Men (ECD)

The External Continence Device for Men is a new method for urine control, used successfully in NASA manned space missions. The ECD seals to the tip of the penis using hydrocolloid, a gentle adhesive used in wound and ostomy care. Urine is directed immediately into a leg or bedside collection bag. The seal around the urinary opening keeps the skin dry, eliminating shaft wounds or infections. Intermittent catheterization can be performed while the ECD is in place. The ECD is typically a daily-use product. The ECD must be applied accurately to ensure proper urine drainage.

Intermittent Catheterization

Difficulty emptying the bladder is known as urinary retention. This can

occur for individuals with MS when demyelination affects the area of the spinal cord that signals the urinary reflex. Retention can result in complications including damage or infection to the bladder or kidneys. Intermittent catheters, or straight catheters, can be a solution for men or women who either partially or completely retain urine. In this method, an aseptic or clean reusable catheter is introduced into the bladder to drain retained urine. After the bladder is empty the catheter is removed. This process is typically performed 3 to 5 times daily. Intermittent Catheterization seldom causes infection if used properly, which is one of the main attractions as opposed to indwelling catheters.

Clamps and Squeezers

Male compression devices, often referred to as penile clamps or cuffs, are made of foam or metal. The clamp is applied to the penile shaft and tightened to exert pressure sufficient to prevent urine flow. These devices must be released every 2-4 hours in order to empty the bladder and prevent crush injuries to the penis. Significant risks exist for penile clamp users. Improper use of these devices can cause penile and urethral tissue damage, penile edema (swelling), pain, and obstruction. Additionally, bladder problems and infections can occur if the clamp is left on too long and the bladder is not allowed to drain.

Pessaries

Women with MS may experience pelvic

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■ Urine Control for Individuals with MS

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prolapse, a stretching or weakening of the muscles that support the pelvic organs. Pelvic prolapse can result in stress incontinence, the involuntary release of urine during physical exertion (coughing, lifting, laughing). A pessary is a soft, rubber compression device inserted into the vagina that rests against the cervix. Pessaries lift and support the pelvic organs, improving urinary control for women who have had limited success with pelvic floor strengthening or Kegel exercises.

Any method used for managing incontinence should be chosen after consulting your healthcare professional. If you have any further questions about the methods of managing incontinence, there are a number of sources of product and procedure information.

National Association for Continence (NAFC) – www.nafc.org - 1-800-BLADDER

Simon Foundation for Continence - www.simonfoundation.org - 1-800-23-SIMON

National Multiple Sclerosis Society – 1-800-FIGHT MS

NMSS Brochure - Controlling Bladder Problems in Multiple Sclerosis
by Nancy J. Holland, RN, EdD

Medicare Coverage for MS Drugs

Funding is still available in the nationwide Medicare demonstration project covering certain therapies for patients who have multiple sclerosis. Applications will be accepted until the patient slots or funds for this project run out.

For those selected to participate in the demonstration, Medicare will cover 75% of MS drug costs – more for those with low incomes – and coverage will allow patients to inject MS therapies at home. Co-payments under the demonstration project may be an obstacle for some people, however, there is financial assistance available if you qualify.

For those with limited incomes at or under 150% of the federal poverty level (about \$14,000 individual/\$19,000 couple), Medicare will provide co-payment assistance. For individuals with annual incomes above 135% of the FPL who cannot afford co-pays under the demonstration project, assistance may be available through the National Organization for Rare Disorders (NORD).

For additional information concerning this demonstration project, please visit: http://www.nationalmssociety.org/medicare_demo.asp or call (NORD) at 1-800-634-7207, or Trailblazer Health Enterprises at 1-866-563-5386, TTY Number: 1-866-563-5387



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

Biogen Idec Suspends Marketing of Tysabri

Biogen Idec and Elan Corporation, the makers of Tysabri (natalizumab), have voluntarily stopped clinical trials of the drug and suspended its commercial distribution. Tysabri had been approved by the FDA last November in an accelerated process after 1-year reports from two 2-year studies demonstrated the drug's safety and effectiveness as a treatment for MS.

The decision to pull Tysabri was announced on February 28, 2005, after one person died from progressive multifocal leukoencephalopathy (PML), a rare nervous system disease, and another person became seriously ill with possible PML. Both of these individuals had been treated with Tysabri in combination with weekly Avonex (interferon beta-1a) injections during the SENTINAL trial. They developed these serious complications after the end of the trial, when they were being followed for a post-marketing study. Each person had been taking the combination therapy for over two years.

PML is a rare, rapidly progressive disease of the central nervous system that primarily affects people with a severely compromised or suppressed immune system (such as individuals who have received organ transplants, patients with cancers such as leukemia, or patients with AIDS). PML is caused by the activation of the JC virus, which is a latent virus present in 80% of healthy adults. How and why the JC virus becomes active is not fully understood.

According to statements from Biogen Idec and Elan, approximately 3,000 people

have been taking Tysabri in clinical trials of MS, Crohn's disease, and rheumatoid arthritis. There have been no other reports of PML in anyone in the MS trials taking Tysabri (either alone or in combination with Avonex or any other medication) or in participants in other clinical trials.

Moreover, there have been no reports of PML in people taking Avonex alone, either during clinical trials or during post-marketing follow-up.

In addition to clinical trial participants, Biogen Idec and Elan report that since the November 2004 approval of Tysabri, 5000 patients with MS have been prescribed the medication by their personal physicians. These patients are advised to consult with their physicians about other treatment options.

Biogen and Elan made the announcement after consulting with the FDA. The companies are currently evaluating all Tysabri-treated participants from their clinical trials and bringing together a panel of experts to better understand the possible risk of PML in people who have taken Tysabri. The outcome of these evaluations will determine the future of the drug.

The National MS Society was distressed to learn of these very sad events, and our deepest sympathies go out to both families.

We commend the quick action Biogen Idec and Elan have taken in voluntarily

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■ Biogen Idec Suspends Marketing of Tysabri
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suspending the use of Tysabri while they investigate the possible link between Tysabri and PML.

It will be disappointing if the investigation suggests that Tysabri cannot be safely returned to the market to treat MS. There are, however, five other disease-modifying drugs currently approved and available for MS, and there are more than 100 clinical trials currently underway looking at new or improved therapies for the treatment of the disease.

We will continue to advise Society members and the public as new information becomes available.

For updates, check our Web site, nationalmssociety.org, or call our nearest chapter at 1-800-FIGHT-MS. Information from the FDA is available at www.fdagov/cder/drug/infopage/natalizumab.

Financial Assistance Available

The Utah State Chapter is pleased to announce the Financial Assistance Program. The Financial Assistance Program is designed to help those with MS during times of great financial need. If you need financial support with durable medical equipment, auto/home modifications, short-term respite care, chore service, transportation to medical appointments, or if your gas or electricity is about to be shut off, apply today!

Medical bills, on going personal care, water and phone shut-off, and food are not covered. Your application will be considered by the Financial Assistance Committee, which meets on the first Tuesday of every month.

To apply for financial assistance, contact DeeDee Fox at 801-493-0113 or deedee@fightmsutah.org. Visit www.fightmsutah.org to download the Financial Assistance Program Application.

In Remembrance of Tina Johnson

The Utah State Chapter would like to pay tribute to a woman who served many in the MS community.

Although Tina Johnson passed away earlier this month, her memory will remain strong for those who knew her.

Tina will be remembered for advocating for the rights of Utahns with disabilities. Through her volunteer work in government relations, she joined many local coalitions that fight for the rights of people with disabilities. She became very educated about the Americans with Disabilities Act, Social Security Disability,

Medicare/Medicaid, Home Health Care, Nursing Home Issues, and Transportation Issues for people with Disabilities.

Tina served as the chairman of the Utah Chapter Government Relations Committee, and led the Newly Diagnosed and Salt Lake MS Support Groups. In 1997, the Utah State Chapter presented her with the MS Champion of the Year Award for her efforts.

The Utah State Chapter would like to offer a most sincere heartfelt sympathy to her loving husband Art.

How I Survived Dating with MS

By Kai Duponte

I was diagnosed with MS seven years ago. I was married then, I thought happily. I remember feeling grateful that I was with someone who would stick with me through this Life Challenge. I realize now that a huge red flag that should have clued me into the future was my ex-husband's reaction to the diagnosis. I needed to comfort him. It was all about him then and continued that way for the next four years, and then he was gone.

Paving a future for myself alone was scary. The thought of dating again was even scarier. I focused on my friends and my work and stayed away from the dating scene at first. When I did start to date, I found the 'scene' very different than before, when I was younger and I didn't have a chronic disease hanging over my head. I couldn't hang out at 'discos' (I'm aging myself just using the term) and find another husband. I am finally in a good relationship now and am ready to share some suggestions that may help others.

Some experiences that I've had and suggestions for others follow:

- Depending on the apparentness of your symptoms, you may have the dilemma of when to 'disclose' your illness. I tried the first date—that was a sure way to ensure I wouldn't get a second (I have heard the first date does work, though, for some, and may be necessary if your symptoms are apparent).
- HOW do you tell your date? I tried the light, airy approach—"it's really not a big deal, thought you might wanna know, but it's REALLY not a big deal..." (the problem with this approach is that there are some

bad times and you want someone who will stick with you through them). I tried the serious approach, hoping to bring forth the knight in shining armor I hoped would be there. Maybe I don't attract the knights (I have a very self-sufficient personality). When you run into the right person, a sign will be that talking about

your illness will come naturally.

- You will want to realize that you will lose out on the possibility of some relationships because you cannot do the things that your date likes to do; don't take it personally. I live in Hawaii, where hiking is a popular hobby. I used to love to hike. Now that I can no longer do so, I lost a commonality that

did mean (I believe) the end of one potential relationship. You will want to make sure that you don't jeopardize your health to try to do things your date likes to do, such as exposing yourself to the hot sun or hiking (I suggested that I try to accompany my date hiking, which would have been a disaster).

- Another dilemma is how and when to be more descriptive about your symptoms. I struggled with telling my partner about my bladder problems. Talking about those kinds of issues was a turn-off for my ex-husband; was I willing to 'turn off' another man? Explaining the depression and the fatigue that comes and goes with MS is important, preferably at a time when you are emotionally stable.
- Another relationship issue was the balance between being a caregiver and needing to be taken care of. I am a caregiver by nature. I love to cook, serve and clean up. All of this is more than fine when I am



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well. The dilemma here is that I am not always well. I found the key here to be communication with my boyfriend while I was feeling well. I told him that I don't always feel able to take on the care giving role and that I hoped he would be supportive during those times. His response to all of the above concerns was one of acceptance. He said that he would be glad for the opportunity to take care of me—good response, and one of the reasons he's still around (in my life).

- One of the areas that I need to be careful of is the feeling that I need to 'make up' having the deck stacked against me by being extra-cheerful and fun to be around whenever possible. That can be draining and can't continue forever.
- Another challenge that I've had is the understanding the challenges my potential mate was facing. Those of us with MS need to realize that the friends and family of those who are dating us may be advising them to stay away from us and that our potential mate may be having to make the difficult decision to ignore that advice in order to stay with us.
- Another area I've found helpful is in modeling how I want to be treated by showing sincere concern when my boyfriend experiences health problems.
- A situation I know will be difficult, but has not come up yet, will be having to

take care of my mate with a contagious illness (cold, flu) without exposing myself to it. I will need to ask cooperation from him with this.

- I find that I try to limit my complaining about things to the times when I am REALLY hurting. I'm always conscious about not wanting to be viewed as a hypochondriac.

I have found that I no longer have energy for the fluff that other women put up with. A man who does not show himself early on as someone who is worth my time and effort will not last long in my dating life. It's just too much wasted effort, and I don't have that kind of energy to burn. The characteristic that I look for now in a mate is very different than the ones I valued—before. The most important characteristic to me in a mate is a certainty that the person will stick with me through the bad times. I have had one man run away when times got tough; I'm not willing to repeat history.

Kai Duponte has a Master's degree in Social Work, and is the Project Director of the Hawaii Child Welfare Education Collaboration at the University of Hawaii School of Social Work. She became a voice for people with MS in 2000, when she advocated for equal access to the ABC drugs and to end discrimination against people needing injectable medications.

Physical Therapy

AREA	TIME	LOCATION	CONTACT
Salt Lake	Physical Therapy Tuesday/Thursday	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

SPLORE River Rafting Trips

Summer is just around the corner and it's time to get outdoors. Enjoy the beauty of Utah, the adventure of white water rafting, the natural high of climbing a mountain or navigating a canoe, and the success of overcoming obstacles. With SPLORE, you can do all of this with people who are passionate about two things: the outdoors and people with disabilities!

SPLORE is a Utah based, non-profit organization dedicated to providing life-enhancing outdoor recreation and education to people with disabilities and specialized needs. Over the past 26 years, SPLORE has created opportunities for people of all abilities to participate in meaningful outdoor adventures in Utah.



SPLORE understands the needs of our clients and customizes each program around those needs. Scholarship opportunities are available and are based on income levels.

To reserve your spot, please contact the SPLORE office at 801-484-4128 or visit their Web site at www.splore.org.

Family Day at the Stingers Baseball Game

Family Day is coming up again! This is always a fun event. Last year we had the largest turnout for any program at the Salt Lake Stingers so we decided to do it again! This year we will watch as the Stingers take on the Omaha Royals.

Date: May 12, 2005

Time: 6:30 pm

Location: Franklin Covey Field



The whole family is invited for dinner and the game. There are sure to be fun things for family members of all ages. Seats will go fast, so call to reserve your seat early! You may register online at www.fightmsutah.org or by calling the chapter after April 12^h.

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 before attending a group to ensure the correct time and location of the group.

AREA	TIME	LOCATION	CONTACT
Bountiful <i>Scrapaholics</i>	3rd Wednesday 6:30 - 8:30 p.m.	Davis County Library 725 S. Main Street	Julie Doherty & Sandi Hill 801-292-6040 / 801-543-1915
Cedar City	3rd Saturday 10:00 a.m.	Chamber of Commerce (Enter west doors)	Linda Lohrengel 435-586-8001
Lehi	3rd Thursday 7:00 p.m.	Best Western 195 S. 850 E.	Kim Horinek 801-789-3164
Logan	3rd Saturday 1:00 p.m. - 3:00 p.m.	Independent Living Ctr. 1095 N. Main Street	Sally Anderson & Monica Eames 435-752-8270 / 435-245-4919
Ogden	3rd Wednesday 7:00 p.m.	Roy Library 1950 W. 4800 S.	Barbara Schneider & Ginger Saltz 801-731-7088 / 801-737-0764
Provo <i>Caregivers</i>	1st Thursday 7:00 p.m.	Northwest Plaza #6 1134 N. 500 W.	Brenda LeVasseur 801-489-9105
Provo	3rd Thursday 7:00 p.m.	Northwest Plaza #6 1134 N. 500 W.	Laurie Towers & Leslie Walkers 801-766-6029 / 801-756-7263
Price	1st Tuesday 7:30 p.m.	Health Department 28 S. 100 E.	Danny Velasquez 435-637-0712
Salt Lake <i>Beyond MS</i>	Every Wednesday 7:00 p.m.	Utah State Chapter 2995 S. West Temple	Beverly Trabanino & Cheryl Hyman 801-534-1525 / 801-886-0256
Salt Lake <i>Progressive MS</i>	1st Thursday 7:00 p.m.	Utah State Chapter 2995 S. West Temple	Heather Horne 801-262-5967
Salt Lake <i>New Horizons for Newly Dx</i>	2nd Thursday 6:30 p.m.	Utah State Chapter 2995 S. West Temple	April Adams 801-263-1358
St. George	4th Saturday 10:00 a.m. - 12:00 p.m.	Knight Education Ctr. 300 E. 600 S.	Ruby Edmondston 435-674-3533
Vernal	3rd Tuesday 6:30 - 7:30 p.m.	Vernal City Offices	Vernie Heeney 435-789-1903

When it comes to multiple sclerosis,
timing is everything.

Treating your MS early can help change the course of its progression. Ask your doctor about treatment options, and call MS LifeLines™ to find out what you can do to help fight MS. Mention this ad when you call to receive a free magazine that tells my story.



MS *LifeLines*™

Teri Garr
Diagnosed with MS in 1999

1-877-447-3243 www.MSLifeLines.com

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Utah State Chapter

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