

Utah State Chapter

Summer 2006

chapter news and events	3-7	volunteerism	27-30
research	8-12	tributes & memorials	31
team talk	13-22	knowledge & programs	32-34
advocacy	23-25	wellness programs	35-38
discovery circle	26		

ms connection

Utah State Chapter

The Utah State Chapter Has A New Home!

he Utah State Chapter of the National Multiple Sclerosis Society opened a

new facility on July 1, 2006 at: 6364 South Highland Dr., Suite 101, Salt Lake City, UT 84121.

This new space enabled the Utah State Chapter to expand the services offered to its clients to include: private meeting rooms where clients may meet with staff one-on-one; ample

meeting space to hold educational programs and support groups; a private client internet access area; increased work space for volunteers; improved office accessibility for people with MS; easier freeway access; and more.

"I am very excited about the new location and the way it will improve our ability to pursue the

mission of the National MS Society, to end the devastating effects of MS," said Tami Featherstone, Chapter President, National MS Society Utah State Chapter.



The New Chapter Office is located

just off the freeway at 63rd South

and Highland Drive in Salt Lake City.

"I am very excited about the new location and the way it will improve our ability to pursue the mission of the National MS Society." Should you wish to contact the Chapter the new phone number is 801-424-0113, press option 1 for

information about MS or a chapter program, and option 2 to speak with Chapter staff about events. Clients may continue to reach the chapter at 1-800-FIGHTMS or www.fightmsutah.org.











Ask the Neurologist

Series Through Fall 2006

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

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 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:

Salt Lake City

• Tuesday, August 29th, 2006 Dr. Evan Black

• Tuesday, September 26th, 2006 Dr. Dana Dewitt

• Wednesday, November 1st, 2006 Dr. Elena James

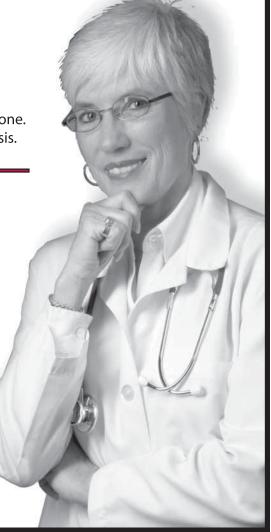
Location: Marie Callendar's • 1313 South Foothill Drive

Northern Utah

Thursday, November 2nd, 2006 MS specialist-TBA
 Location: Maddox Ranch House (Lodge)
 1900 S. HWY 89 • Perry, Utah

Please Join Us!

Dinner and discussion compliments of Teva Neuroscience. Call 1-866-227-9788 ext. 4208 to register.



CHAPTER NEWS

Upcoming Events

Long Term Care Seminar

August 31, 2006Utah State Chapter Office
6364 S. Highland Drive, Suite 101, Salt Lake City

MS:101 Newly Diagnosed Seminar

September 12, 2006 – Evening Utah State Chapter Office 6364 S. Highland Drive, Suite 101, Salt Lake City

28th Annual Dinner of Champions

September 13, 2006

Downtown Marriott 75 S. West Temple, Salt Lake City

Empolyment Conference

October 10, 2006 6:00 - 9:00 p.m. Karen Gale Miller Conference Center SLCC Campus, Sandy 9750 South 300 West

Caregivers Conference

October 21, 2006 8:00 a.m. - 2:30 p.m. South Towne Expo Center

Annual Meeting & Open House

November 9, 2006

Utah State Chapter Office 6364 S. Highland Drive, Suite 101 Salt Lake City, UT

Women Against MS Champagne Luncheon and Fashion Show

February 17, 2007Little America Hotel

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801.424-0113 / 800.FIGHT MS

Publication of the National MS Society Utah State Chapter 6364 S. Highland Dr., Suite 101 Salt Lake City, UT 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 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
Serono Neurology	39
Biogen Idec 21	& 40

ms connection

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The Chapter Celebrates a Successesful 2006 MS Walk and the 20th Anniversary MS 150 Bike Tour

he National Multiple Sclerosis Society Utah State Chapter is pleased to announce that the statewide MS Walks had over XXX participants and raised a record-breaking \$427,000; followed by an outstanding response to the 20th Anniversary MS 150 Bike Tour with over 2500 participants combining to raise more than \$1,247,000 – and the donations keep rolling in. Money raised through the Society's two biggest fundraisers will fund client programs and MS research, moving us one step closer to our mission; to end the devastating effects of MS.

The 17th Annual MS Walks, presented by Harmons, Your Neighborhood Grocer®, began their routes at the Gateway in Salt Lake City, Christensen Park in St. George, Exchange Park in Provo, Searle Pavilion in Vernal, the Lorin Farr Park in Ogden, and the Providence Shopping Center in Cedar City. This year the MS Walk's celebrated our "fundraising stars," with the theme, the MS Hollywood Walk of Fame. Participants came



Ogden walkers enjoy a moment in the sun at Lorin Farr Park



Mountain America Credit Union shows their commitment to walk the walk to fight MS rain or shine

CHAPTER NEWS

■ 2006 MS Walk and the 20th Anniversary MS 150 Bike Tour

— continued from previous page

dressed as their favorite Hollywood star to add to the fun and festive atmosphere.

"This year's MS Walks were unlike any we've had before," said Tami Featherstone, Chapter President, National MS Society Utah State Chapter. "We had an incredible turnout. It's wonderful to have so many people in the community support the fight against MS. It is because of their fundraising efforts that we will one day find the cure for this disease."

MS 150 Bike Tour

More than 2,500 participants gathered at the Cache Valley Fairgrounds on June 24th and 25th to participate

in the 20th Anniversary MS 150 Bike Tour, by far the National MS Society's largest and most exhilarating event. Participants in the MS 150, presented by Harmons, Your Neighborhood Grocer®, toured 40, 75, or 100 mile routes each day on the scenic roads of Cache Valley. Riders of all ages had access to rest stops supplied with food and water, first-aid support, and supply, assist, and gear (SAG) vehicles along the route. The yearly



Riders of all ages and abilities joined the pack to ride all over MS.

continued on following page

ms connection

Chapter Staff

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■ 2006 MS Walk and the 20th Anniversary MS 150 Bike Tour

— continued from previous page

fundraiser made over \$1,247,000 to support MS research, and programs for those living with MS. Utah's MS 150 is the largest organized, two-day cycling event in Utah.

Over the weekend participants camped at the Fairgrounds or filled up the Logan hotels; all of which were sold out. At the Fairgrounds — home base for the MS 150 — a festival atmosphere came to life with live bands, team tents, great food, and fun for the entire family. Saturday night, riders enjoyed a pool party and an awards dinner presentation with Bill Allred of X96 as the emcee.

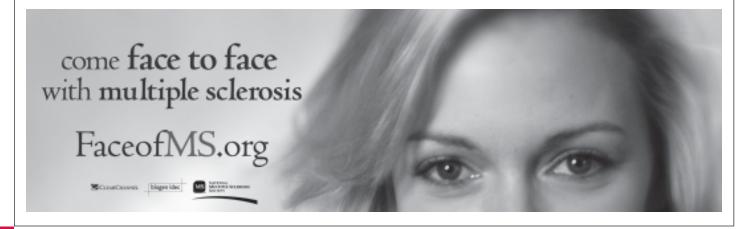
To learn more about either event, or to view the photo gallery, visit www.fightmsutah.org.



Team Trisha's Strength shows off their umbrella decorations at the St. George Walk



Frank Roskelly shown here accepts a MS 150 Legends Award for 20 years of riding to cure MS. Also receiving Legends Awards, Jeff Pease (retiring MS 150 Chair), and Tony Furano and the Furano Family (for 20 Years of feeding cyclists at the MS 150 lunch stops)



Thank You Sponsors

The National MS Society would like to thank the following gold sponsors for their generous support of the 2006 MS 150 Bike Tour:

Harmons, Your Neighborhood Grocer

X96

KSL

KLZX 95.9 Classic Rock

Bingham Cyclery

Saturn

Fidelity Investments
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FedEx

The National MS Society would like to thank the following gold sponsors for their generous support of the MS Walk:

Harmons, Your Neighborhood Grocer

KSL

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Western Neurological Association

Huish Detergents

Freschetta Pizza

Open Imaging

KSOP

Thank You!

Save the Date - Wednesday, September 13 2006 New Location: Marriott Downtown, 75 S. West Temple, Salt Lake City

It is with great pleasure that the National MS Society Utah State Chapter invites you to join us at a black-tie gala honoring the heroes in our community! Please join us as we present the T.K. McCarthey Silver Hope Award

to a man who has inspired many,

Reverend France Davis

Thank you for your support and loyalty in the fight to end multiple sclerosis. To reserve your table please call 801-493-0113

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

To learn more call 1-800-FIGHT-MS or visit www.fightmsutah.org

RESEARCH SUMMER 2006

A Gift for the Future: Tissue Donation

Researchers study MS with cutting-edge technologies. But, it takes more than technology to do the job. Sometimes researchers also need tissue from people who lived with the disease.

issue donations support the Society's MS Lesion Project, an initiative of Promise:2010, which led to the discovery that there are four types of lesions, each of which can now be identified by MRI. Understanding lesion patterns and identifying the immune factors involved with tissue destruction can provide information about why the disease affects people differently and could lead to developing individualized treatments.

The decision to donate should be shared with family and doctors in advance so that tissue may be taken within a few hours of death. Minimal paperwork is involved and there is no cost to the donor or family. Strict privacy practices assure that tissue and medical records are not identified by name. Donation does not prevent normal funeral arrangements.

There is no substitute for this gift from individuals and families committed to MS research. Simply contact the Rocky

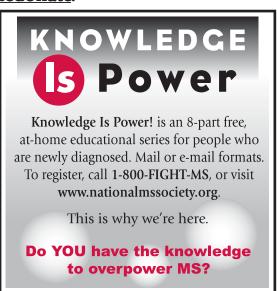


Mountain MS Center Tissue Bank, 303-788-4030, ext. 105, www.mscenter.org, or the MS Human Neurospecimen Bank at UCLA, 310-268-3536,

 $\underline{www.loni.ucla.edu/uclabrainbank}.$

Both are supported by the Society. Information and links to these sites can be found at

www.nationalmssociety.org/tissuedonate.



RESEARCH ms connection

Mickey and Minnie Have Different Myelin

More and more, research shows males and females really are different.

ake myelin (the insulation surrounding nerve fibers that is damaged in people with MS.). A new study shows that myelin-making cells, called oligodendrocytes, have different life-spans in male and female mice.

When researchers compared the number of oligodendrocytes in the brain and spinal cord of male and female mice, they found male mice had 20–40% more oligodendrocytes than females. Moreover, the male oligodendrocytes contained twice as many genetic instructions for making myelin proteins.

Looking further, they found female mice produced greater numbers of new oligodendrocytes than males—but with a shorter lifespan.

Females also had higher levels of a protein associated with myelin damage.

To see if there was a hormonal connection, researchers removed a male sex hormone (testosterone) from the male mice, which shortened the life of their oligodendrocytes. This suggests that testosterone keeps the oligodendrocytes revved up longer, possibly providing greater protection to the nervous system.

This study was funded through the National MS Society's Initiative on Gender Differences in MS and is reported in the February 2006 issue of

The Journal of
Neuroscience. It may
shed more light on why
women are twice as
likely to develop MS as
men. Exploring the role
of gender has already
led to clinical trials
studying sex
hormones in people
with MS. (See AAN
Round Up on page 10
for more
information.)

"When researchers compared the number of oligodendrocytes in the brain and spinal cord of male and female mice, they found male mice had 20–40% more oligodendrocytes than females."

-SUMMER2006

AAN Round Up

The results of more than 200 MS-related clinical trials and studies were presented at the American Academy of Neurology's 58th Annual Meeting in San Diego this past April. Among the highlights:

esearchers reported on the results from a phase 2 clinical trial of an oral MS drug, **FTY720**, or Fingolimod. Relapse rates and inflammation as detected by MRI were significantly reduced in participants taking the drug, which blocks T and B cells from the central nervous system where they can cause MS-related damage.

A study funded by the National MS Society's Initiative on Gender Differences in MS showed that applying AndroGel (a testosterone gel) to the skin of 10 men with relapsing-remitting MS for one year improved cognitive function and slowed brain tissue loss.

An early study showed that a combination of **BHT-3009**, an immune system modifier, and **Lipitor**, a cholesterol-lowering drug, was safe and may provide protection from immune attack in MS.

he results of the **BENEFIT** study showed that, of 487 people at high risk for developing MS, the half given an inactive placebo was 50% more likely to develop definite MS than those given Betaseron (interferon beta-1b). Participants in this trial had CIS, or clinically isolated syndrome, meaning they each had a single demyelinating event, but had not been diagnosed with MS.

A. Sibley, MD, of the University of Arizona, Tucson, received the 2006 John Dystel Prize for Multiple Sclerosis Research, given jointly by the National MS Society and the AAN. Dr. Sibley's research showed how infections can influence the occurrence of MS relapses.



ms connection

Intermountain Multiple Sclerosis Project: Research Aimed at Understanding the Genetic Elements of Multiple Sclerosis Susceptibility Seeks Participants

The Intermountain Multiple Sclerosis Project (IMSP) is a new study at the University of Utah which investigates factors that contribute to the development of MS and examines factors that may be markers of disease activity.

S is seen as the interplay of genetic susceptibility, environmental exposure, and deregulation of the immune system.

MS is probably triggered by an environmental factor in persons who are genetically susceptible. The role of genes and environment are not fully understood in MS. Determining factors influencing familial tendency in MS would be a major step to understanding the roles of genetics and environment in MS.

The Intermountain Multiple Sclerosis Project will address genetic factors in MS disorders by studying participants and their families. Individuals with MS can be evaluated in population studies that focus on susceptibility factors related to the illness. In addition, families with three or more affected individuals are also significant for our investigation of genetic susceptibility in MS. These family studies will involve analysis with a unique population database and advanced computer programs to find responsible disease genes for MS.

The research is especially interested in participants and families from different ethnic backgrounds. For example, individuals and families of Northern European and Greek descent are especially valuable in this type of investigation.

Blood samples will also be screened for markers of autoimmunity, inflammation, and neurodegeneration. In addition, researchers will search for abnormalities that may assist in the diagnosis of the MS.

For more information on the IMSP or genetics of multiple sclerosis contact Dr. John Rose, MD (801-585-7909) or Dee Husebye, Study Coordinator (deehusebye@genetics.utah.edu)

SUMMER2006

Viral Triggers in MS Exacerbations Study Seeks Participants

University of Utah School of Medicine physicians are seeking persons with MS to participate in a new research study. This study will investigate the specific viruses responsible for common colds and their relationship to MS "attacks" (also called "exacerbations" or "relapses").

of U doctors are seeking approximately 60 MS patients with colds who have experienced nasal or respiratory symptoms for only one or two days. Participants will be asked to come to the University of Utah Neurology Clinic, provide informed consent, samples of blood and nasal mucus, and have a neurological examination. One or more additional visits will be required during the subsequent five weeks.

Participation in this study is free for study subjects – and entirely voluntary. It is a good opportunity for persons with MS to contribute to locally-conducted research into the causes of MS attacks. The study is strongly supported by the Utah State Chapter.

Dr. John D. Kriesel, Assistant Professor of Internal Medicine and Infectious Diseases, will head the two-year study funded by the National Multiple Sclerosis Society (in the amount of \$242,900). Dr. John Rose, Professor, Department of Neurology, and Dr. David Hillyard, Medical Director Molecular Infectious Disease, ARUP Laboratories, are the Utah coinvestigators involved with the study. The study will also involve Dr. William Sibley, Professor of Neurology at the University of Arizona, with an additional study site at the Northwest NeuroSpecialists MS Clinic in Tucson.

Persons interested in receiving more information about the study are encouraged to contact:

Mark McKeough
Study Coordinator
Viral Triggers of MS Study
Phone: 801-581-6406
Email:
mark.mckeough@hsc.Utah.edu

TEAM TALK ms connection

Thank you to all the team captains who helped to make our MS Walk and MS 150 so successful!

MS Walk Captains

Kimberly Adams Heidi Adams Shawna Ahlborn Angie Aikens

The Team with the Tie Dyed Shirts Team Discovery Team Costco Cares Team Mountain America Credit Union

Danielle Alexander Stephen Allen Gina Anderson Brandi Angel Christa Aquilla **Heather Atkin** Matt Bagby Claudia Baker

Team DiggleSLC Team DATC-VICA Team Lainas Courage Team The Chocoholics Team Goldman Sachs Team Atkin Family Team Focus Youth Ministry Team Mountain America

Credit Union

Justine Barber Corban Barbuto Ruth Barrow Diana Bateman Mckensie Baver Carrie Bennett Cheryl Bennett Nicholas Bielaczyc Laurel Bills

Holly Bird **Christie Black** Carol Blackburn Tanya Blake

Heather Boies Logan Bowen Brenda Brasher

Travis Brgoch Charles Brinkerhoff

Caitlin Bryant Mandy Bunn Leslie Burkett Toby Bushman Darla Butterfield **Tamara Carter** Cindy Castro

Tammy Chacon

Team Wisdom for Life Team TAG-A-LONGS TEAM SUNSHINES PALS Team Diana's Dream Team WNA Team Bluff Street Babes Team Nightwalkers Team Bielaczyc Team Extracting Mgrs Team Flyin with the Birds Team Equal-I-Zer Team Barberettes Team Blake Family

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Team Fannypack Team Saving Grace Team Troop 1237 Weight Watchers-**Biggest Losers**

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Team Condies 4 the Cure

Team Sarah

Team Hobbits for Health Team Webco Recordettes

Team Sanich Team LaPoint Ford Team Ames Volunteers Team Beaver's Best Team Fun4Grandma Team Watchers

Team Walking For A Cure

Team Bug Team UPS Team Jazzettes Team Aspen Homes Team Mystery Solved Team Friends with Hope Elaine's MS Walk Team

Team Starbucks Team IKON Team MSPEEDY Team Tim Dahle's Team

Weight Watchers-Nightwalkers Team Hurricane Rehab Center Team Friends

Team Wee Haw Team Havana Team Paisley

Team Alpine Garrison

SUMMER2006 TEAM TALK

Team Captains

— continued from previous page

Team Joyce's Crew Christopher Fox Elizabeth Frith Team LEAPING LIZARDS Katherine Frith Team LEAPING LIZARDS Mary Furness Team Myelin Builders Jennifer Garner Team Garner Group Michelle Gehrett Team Poppy Walkers Jennifer Gillett Team Frozen Waffles Patricia Glenn Team Glenn's Gal's Kelly Gomez Team Gomez Landscaping Ann Gomez Team Gomez Landscaping Devin Gongora Team Walking Jankes Team Go Goodwin Paulette Goodwin Rebecca Greenwood Team Multiple Striders Penny Gutierrey Team Lightning Bolts Tracie Haaksma Team HAAKSMA Beverly Hall-Knudson Team Dreamweavers Katie Harrison Team Katie's Crew **Kate Harvey** Team MS Fits Tyson Haslam Team Tysdog Anna Hawkins Team Worldmark LaTonya Heaton Team Hurricane Rehab Vernie Heenev Team The Mayor's Own **Team Lochner Lionhearts** Rebecca Henson Kimberly Hernandez Team Steel Her Jen Nathan Higgs Team Higgs Team Stan Team Dennis' Shoes Team 4-H Walks For Becca

MaryJane Higley Debbie Hill Connie Holgate Susan Hopkins Team MS Cruisers Christina Hopkinson Team The Hopkinson Team

MarDee Hoslev Team Jensen Erin Howell Team 4 Breck Sophie Humphreys Team Mountain America

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Robert Ingleby Team Artistic Entertainers

Ellen Jackson Team Rosemary Venice Jensen Team All the brains &

some braun

Stephanie Jewkes Team DaisyJewkes

Tricia Johnson Team Delightful Dames & Dears

Cindy Johnson Team The Survivors

Sally Jones Team Nash Kelly Kelso Team Leclerc Carol Kinder Team Fighters Debbie King Team Deb's Family Jessica Knickerbocker Team Cubies Unite **Deidre Knox** Team Roll On Mindy Kopelson Team Fantastic Four Alisa Kramer Team Adams Heather Krapsicher Team Nexus

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Team Ludgate's fight MS Team Soles for Sisters Jan Luger

Sean MacKay Team Raptors

Jennifer Magee Team Walking for Mom Cassandra Manders Team Wal-Mart Walkers

Andrea Mangum Team Fannypack Team 649 CLSS **Kursten Martinez** Patricia Mayor Team PCMC Cindy Maxwell Team Roper Amy Mayberry TEAM TURTLE Danielle Mavo Team Cat Clan Donald McArthur Team Gubler Goers

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Loraine Militello Team Grace Gadabouts Mandy Miller Team Eam Nick Nack Kim Milligan Team Bubble Butts MeganMoore Team The Baristas Michele Morgan Team VMS Against MS

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Systems

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Krista Nash Team Lady Leggers

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Team Seestas Plus Marianne Nelson Jackie Lvn Nielsen Team Walkets

Stanton Nielson Team Utah Sigma Sae Team Mystery Solved **Dennis Nordfelt**

Jody Norton Team SOS

Samantha Nyborg Team Samantha's Rai

TEAM TALK **ms** connection

Team Captains

— continued from previous page

Jessica Ogden Team Friends Helping Friends Kristen Ott Team Ott Team Sharon Oveson Team SOS **Angelo Papastamos** TEAM TANKERS Mac Pearson Team Cokey-Beano Kristie Pederson Team Steelers Amanda Perkins Warnes Walkers Kevin Pfunder Team Pfunder Pfighters Casey Phelts Team Slowsky's Team Leann's Legion Randy Phillips Elizabeth Piercy Team Lizblizz

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Cami Rimington Team Weebles

Karla Roberts Team Break Away from the

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Hank Schnaubelt Team Red Mountain Trekkers

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Elizabeth Scott Team Grace Gadabouts Debora Seiter Team GOT MYELIN Janet Sessions Team Janet Sessions

Lin Shaffer Team VECC Rodney Shirley Team Walkin Rod

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Dawn Silcox Team Snoopy Carma Slaugh Team MACU Justine Smith Team Cougars

Team White Real Estate Lysa Smith

Associates

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Family Against MS Team Walk N Talk

Jaime Sorensen Brenda Spearman Team Friends of Brenda Linda Stallings Team Linda's Lifesaver's

Terri Stark Team Katie Ashlie Steele Team Steel Herjen David Stephenson Team Rams Shauna Stephenson Team Capture Today

Susan Stetich **TEAM STETICH** Chancee Stoker

Team Warrior Student Counsil Team Team Littlewings Keri Stone

Jacque Stonehocker Team Treasure Anne Sullivan Team Sully Team SPS Alisha Sykes

Natalie Tate Team Just Crawlin' Along **Team Taylor Tigers Dave Taylor Diane Taylor** Team The Taylors Team Firebirds Kendra Taylor Rachel Taylor Team Cure

Sally Teal-Holman Team The Teal Ducks David Thompson Team Jones Paint& Glass **Devin Thomson** Team Walking Warriors **Bonnie Tolman** Team BRT's Friends

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Chayito Woolsey

SUMMER2006 **TEAM TALK**

Randy Doyle

Steven Dwyer

Barbara Fink

Mckell Eldredge

Christine Ferrario

■ Team Captains

— continued from previous page

MS 150 Team Captains

Leslie Allaire Team Wasatch Road Runners

Bill Allred Team x96

Team Expeditors Stacy Ames **Kelly Amott** Team Albertsons

Team KSI Jadon Andersen

Team Halo Lavla Anderson **Brent Arnold** Team Kern River

Diane Atwood Team Seguoia Group Team Vicious Cycle **Roy Bartee** Team Salsa America Jeffery Bean

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Kristi Bergstrom Team CTR-Choose To Ride Lisa Blakemore Team Blakemore's Bikers **Emily Bolding** Team Starbucks Utah Harvey Brown Team Schreiber Cheese

Peddlers

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J Bunderson Team Motivation

Team Good From The Waist Down Brian Bush

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Team Mountain America Ray Carsey

Credit Union

Richard Caruso Team Bush Decor & Construction

Matthew Clark Team Mountain America

Credit Union

Team Snowbird Misty Clark

Team Bonneville Bicycle Touring Club Karen Curtin

Jennifer Cutler Team Saturn Jared Dain Team Quickutz

Team Bush Decor & Construction Jen Decker

Team Singles 41st Ward Andrea Demina

Damian Dennison Team Slipstream

Team Cache Valley Veloists Brian Diamond

Kerry Doane Team Doane William Dolinar Team Iron Eagles Steven Donnelly Team HealthInsight Michael Dotson

Team The Pedlin' Penguins

Team Brighton

Team BAD ASS COFFEE Team Blakemore's Bikers

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Kimberly Gerard Team FLH Wesley Gibbs Team Wes Ken Gibby Team UCCU

Team Little America Hotel Bernhard Gotz

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R. William Habel Team Saints and Spinners

Kim Haggin **TEAM HILL**

Mallory Hamblin Team Bush Decor & Construction

Jake Hardy Team SignThis Martha Harvey Team Discover Rusty Healey Team Bistro

Todd Higley **Team Scott Machinery** Claire Hillis Buck Team Mountain America

Credit Union **Gregory Hinton** Team Wee-Haw

Wendy Hobson-Rohrer Team Wine and Cheese Club Shannon Holden Team Abra Autobody & Glass

Eric Hulphers TEAM HILL

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Thomas Jackson Team Blazing Saddles

Team Stars Ken Jackson Team Flight RaeAnn Jensen Rhonda Joa Huffaker Team Rhonda Dave Jones Team Baker Team Harmons **Gregory Jones** Jason Jones Team Janet

■ Team Captains

- continued from previous page

John Jonkman Team P3

Natalie Kaddas Team Bush Decor & Construction Team Bush Decor & Construction

Matthew Kriech Team ATK

Kevin Kruse Team Bush Decor & Construction

Todd Larsen Team Breeze

Aaron Larsen Team Corre Caminos

Kitty LeValley Team Jewels William Long Team Tina

Mark LongsonTeam Bluff RidersBrett MackayTeam Spin DixieTim MagawMS Team FedExDennis MarcusTeam OSWAD

Michael Mayor Team Saints and Spinners

Jodi McPherson Team Harmons

Annette Mead Team Wells Fargo Utah
Lisa Moore Team Moore Family

Michael Moore Team Tracy
Bret Moulton Team Avonex

Kathleen MyersTeam Amazing SurvivorJeff NewmanTeam Road DogsTerry NoordaTeam Flying Spokes

Martin Nowling Team 'Z' Team - Zions Bank

Mark Nuttall
Mary O'Connor
Linden Olson
Tomi Ossana
Stacy Palen
Team IKON
Team Espoir
Team Moore
Team Figaro
Team The Cyclotrons

Janet Papastamos Team Blakemore's Bikers
Team John Paras Furniture

Mark PasternakTeam Spare TiresMac PearsonTeam Cokey-BeanoJeff PeaseTeam Logan Race Club

Mary Perry Team Ride

Eric Peterson Team Health Quest

Kirk Phillips Team Cheryl

Janice Pinterics Team Watson Pharmacyclists

Jayde Prudden Team Tinderbox

David PugmireTeam Fidelity InvestmentsPaul PugmireTeam Skyline Event Group

Ben Rand Team CEntry
Jon Reese ROCKET

Tara Rollins Team Utah Housing Coalition

Margaret Rose Team RHSM Riders

Keith Rossberg
Brahim Salami
Jane Santora
Joseph Sepulveda
Daniel Severinsen

Team Bush Decor & Construction
Team Zaramedia
Team DogMeat
Team DNA Cycling
MS Team FedEx

Daniel SeverinsenMS Team FedExChris SimmonsTeam StarsBrian SmithTeam Cyprus Credit Union

Spencer Sorensen
Jay Spector
Team BAD ASS COFFEE
Team Cancer Wellness House

Jonathan Springmeyer Team Barbie Cj Stewart Team UTA

John Sumsion
Dan Thirkill
Cindy Thompson
Duane Thurber

Team Performance
Team Sun Riders
Team Qwest
Team UBS

Chris TolsmaTeam Bingham CycleryDan TrueTeam BD Medical

Naomi Vasquez Team Pioneer Valley Hospital

Devin Watts Team Health Quest

Dave Wharton
Jav Whiting
Team Fidelity Investments
Team Bush Decor & Construction

Jay Whiting
Stefanie Wilson
Team Bush Decor & Construction
Team Bush Decor & Construction

Annette Wood Team Hospice Alliance
Jim Yorgason Team Naste



TEAM TALK SUMMER2006

MS 150 Bike Tour

Top 100 Fundraisers

Thank you to everyone who participated in the 2006 MS 150 Bike Tour. Listed below are the top 100 fundraisers as of our publishing date of August 1, 2006. We apologize if your information is incorrect.



Name	Event Team Name	Total
Keith Rossberg	Team Bush Decor & Construction	52803.10
Andrea Bauer	Team Blakemore's Bikers	25000.00
Lisa Blakemore	Team Blakemore's Bikers	11845.00
Denise Bermant	Team Jewels	10000.00
Kitty Levalley	Team Jewels	10000.00
Charles Trentelman	Team Rhonda	7080.00
Dean Peterson	Team Harmons	6000.00
Kevin Kruse	Team Bush Decor & Construction	5835.00
Michael Walters	Team Cyprus Credit Union	5741.00
Peter Taylor	Team Blakemore's Bikers	5606.00
Jim Smith	Team Cyprus Credit Union	5600.00
Bob Harmon	Team Harmons	5550.00
Andrew Sorensen	Team Cyprus Credit Union	5340.00
Jennifer Pratt	Team Cyprus Credit Union	5335.00
Steven Pratt	Team Cyprus Credit Union	5280.00
StevenMcIntyre	Team Espoir	5250.00
Jessica Thompson	Team Cyprus Credit Union	5200.00
Ashley Chandler	Team Cyprus Credit Union	5130.00
Brian Smith	Team Cyprus Credit Union	5000.00
Dana Thompson	Team Cyprus Credit Union	5000.00
Aaron Pauls	Team Blakemore's Bikers	4625.00
Fred Cvar	Team Tinderbox	4565.00
Frank Roskelley	Team Espoir	4287.50
Blaine Blonquist		3535.00
Raul Casillas	Team University Sports Medicine	3125.00
Jane Fischer	Team Blakemore's Bikers	3000.00
Kimberly Gerard	Team FLH	2980.00
Janet Papastamos	Team Blakemore's Bikers	2935.00
Kendall Robins	Team Espoir	2687.00
Kara Reese	ReeseROCKET	2640.00
Blaine Walker	Team Espoir	2625.00
Dan Wilcox	Team IKON	2585.00
Lammert Veenstra	Team Blakemore's Bikers	2515.00
Karen Paine	Team Blakemore's Bikers	2500.00
Hilea Walker	Team Espoir	2500.00
Kristy Haws	Team Stars	2460.00

TEAM TALK ms connection

TEAM TALK SUMMER 2006

Name	Event Team Name	Total
Peggy Hancock	Team Alta	1385.00
Brett Mackay	Team Spin Dixie	1380.00
Kaylee Jensen	·	1380.00
Christine Martin	Team Espoir	1360.00
Greg Colf		1350.00
Steve Horton	Team FLH	1345.00
Todd Lemon	Team MS Team FedEx	1337.00
Todd Larsen	Team Breeze	1336.00
Thomas Jackson	Team Blazing Saddles	1322.00
Robyn Seldin	Team Spinning Dervishes	1310.00
Cade Iverson	Team Little America Hotel	1301.17
Dellene Stonehocker	Team BAD ASS COFFEE	1300.00
Margo Littley	Team Figaro	1295.00
Stephen Bons	Team Bush Decor & Construction	1290.00
David Baird		1271.00
Jack Cole	Team Snowbird	1266.00
Randy Schoeck	Team Blakemore's Bikers	1250.00
Andrea Marwedel	Team Cancer Wellness House	1250.00
Kirt Lewis	TEAM HILL	1243.00
Scott Childs	Team Qwest	1242.00
Martin Neunzert		1230.00
Jim Cooper	Team Albertsons	1221.67

Please contact the chapter if these totals are incorrect; changes are made daily which influence the accuracy of these numbers.



Listen & Learn "Advances in the Treatment of MS"

Wednesday, September 13, 2006 Program time: 6:00 PM MST

Featured Speaker
David Renner, MD

University Medical Center, Salt Lake City, UT

Please register by August 31st to receive materials.

Information is power in the battle against multiple sclerosis (MS). Equip yourself with the facts by registering for this educational opportunity today.

A physician expert will discuss the most current treatment options available, including side effects and dosage requirements.

Whether you are on treatment, tried treatment or are curious about treatment options, you'll learn things that can help you face your MS challenges with renewed strength. Don't miss this free teleconference!



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Top Teams for the 2006 MS 150 Bike Tour and 2006 MS Walk

Thank you to all of the team's who participated in the 2006 MS 150 Bike Tour. Our top 20 teams at the time of publishing were:

Event Team Name	Team Total
Team Blakemore's Bikers	\$106,884.25
Team Bush Decor & Construction	\$103,206.00
Team Espoir	\$58,560.44
Team Cyprus Credit Union	\$52,051.87
Team Fidelity Investments	\$51,356.00
Team Harmons	\$30,120.61
Team Jewels	\$28,249.00
Team Stars	\$25,596.01
Team BAD ASS COFFEE	\$24,913.50
Team ATK	\$22,151.95
Team Albertsons	\$20,021.28
Team Little America Hotel	\$19,029.50
Team Mountain America Credit Union	\$16,693.61
Team FLH	\$16,670.00

Team Rhonda	\$16,011.00
Team University Sports Medicine	\$15,570.00
Team 'Z' Team - Zions Bank	\$14,804.00
Team Brighton	\$14,448.90
Team Cheryl	\$12,230.07
Team Cancer Wellness House	\$10,834.00



Thank you to all of the teams who participated in the 2006 MS Walk. The top twenty fundraising teams as of publishing on August 1, 2006 were:

Team Name	Team Totals
Team The Mayor's Own	\$23,791.00
Team Lightning Bolts	\$14,843.00
Team Goldman Sachs	\$11,405.00
TEAM TURTLE	\$10,292.50
Team The Pfunder Pfighters	\$8,244.66
Team Boies	\$8,127.00
Team HRO	\$5,854.94
Team K's Crew	\$5,807.00
Team SPS	\$5,786.00
Team BD Medical	\$5,121.47
Team The Chocoholics	\$4,859.00
Team Mountain America Credit Union	\$4,373.59
Team VMS Against MS	\$4,336.00
Team Havana	\$4,333.00
Team Beaver's Best	\$4,295.00

Team Mystery Solved	\$4,251.00
Team Gubler Goers	\$3,641.00
TEAM STETICH	\$3,611.00
Team Red Mountain Trekkers	\$3,445.00
Team Amy's Friends & Family Against MS	\$3,404.61



Please forgive us if your team total is incorrect, or if you were not included. These numbers were deemed accurate at the time they were published, changes to team totals are made daily based on new information.

ADVOCACY ms connection

National Surveillance of MS

Knowing how many people are diagnosed with MS each year and how many have MS at present is important information for health-care policy, advocacy, and planning.

ederal agencies and state health departments have not generally tracked chronic neurological diseases such as MS, focusing instead on infectious diseases such as TB. Steps are being taken to change this. In March, researchers from the Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry (CDC/ATSDR) held a workshop to discuss national surveillance of MS and ALS (amyotrophic lateral sclerosis, or Lou Gehrig's disease).

Plans are in the pipeline to develop pilot studies to track MS and ALS in a few geographic areas. The CDC is using MS and ALS to test the feasibility of ongoing surveillance for a number of chronic diseases, in part because substantial work, much of it supported by the Society, has already been done.

The CDC/ATSDR has funded small studies in a few areas of the U.S. where possible MS clusters have been reported. However, it's difficult to determine whether a true cluster exists without solid numbers for the normal incidence and prevalence of MS in a given region.



A surveillance system would establish those numbers. If clusters can be verified, they may provide clues to environmental and genetic risk factors which might contribute to triggering the disease.

Obtaining an up-to-date count of people with MS in the U.S. is one of the issues being considered by the Society's new Task Force on the Epidemiology of MS. (Epidemiology is the study of who gets a disease, its geographic distribution, and events that may contribute to a person's risk of getting it.)

The Task Force will collaborate closely with the CDC/ATSDR in their efforts to develop a national surveillance system for MS. The Task Force will also consider the feasibility of MS studies on environmental risk factors, migration patterns, and racial/ethnic distribution. Better numbers about MS will help the Society to develop research initiatives, service programs, and advocacy priorities.

ADVOCACY SUMMER2006

The Utah State Chapter visits with Legislators on Capitol Hill

2006 Public Policy Conference a Success

This spring, chapter employee Chelsey Butchereit and Government Relations Committee Chair Dale Boam, met with hundreds of other National MS Society staff members, volunteers, and people with MS from across the country.

he meeting took place in Washington, DC where the National MS Society holds its Public Policy Conference each year. During the three day conference attendees were educated about advocacy tactics and current issues relating to MS.

The highlight of each conference is an opportunity to visit with elected officials on Capitol Hill. Each year conference participants converge in solidarity on Capitol Hill to increase awareness of MS and issues related to living with MS. Several hundred visits were made during this day. Dale and Chelsey met personally with Senators Hatch, and Bennett, and Representative Jim



Chelsey Butchereit, Chapter Programs Coordinator Dale Boam, Government Relations Committee Chair, and Representative Jim Matheson met in April to discuss issues relating to MS research and treatment.

Matheson. Staff members from Representative Rob Bishop's and Chris Cannon's offices also met with Dale and Chelsey.

The issues discussed included increased funding for NIH, support for stem cell research, and eliminating Medicare rehabilitation therapy caps.

To learn more about the Public Policy Conference, or to get involved with our Government Relations Committee, contact Chelsey at 801-424-0113.

ADVOCACY ms connection

For SSDI Beneficiaries Who Work or Want to Work

o you receive SSDI (Social Security Disability Income)? The amount of money that can be earned during a "Trial Work Period" has been increased to \$620 per month. Allowable earned income or "Substantial Gainful Activity" income has also been raised—to \$860 per month for people considered disabled but not blind and \$1450 per month for people deemed blind.

To make this work for you

Staying within these limits ensures that SSDI income and medical benefits are not affected. But first, contact the nearest Social Security Benefits Planning Assistance and Outreach program. Despite the awkward initials, people

find that SSBPAO staff specialists are trained to help and have expert advice on all the ins and outs of Social Security's work incentive programs. SSBPAO is housed in community-based organizations, not Social Security offices. For a state-by-state listing, visit www.socialsecurity.gov/work/ServiceProviders/BPAODirectory.html or call our office if you don't have access to the Internet.

COLA all around

Both SSDI and SSI (Supplementary Security Income) beneficiaries received a 4.1% cost of living adjustment or COLA starting January 2006. Call 800-772-1213 or your local Social Security office if you have questions.

Next Medicare Part D Enrollment: November 15 - December 31

f you are currently covered by
Medicare but missed the May 15th
deadline to enroll in a Medicare Part
D prescription drug plan, your next
opportunity to enroll will be during the
open enrollment period Nov 15–Dec 31.
Once enrolled in a Part D plan during
the open enrollment period, coverage
begins January 1, 2007. People on both
Medicaid and Medicare (so-called "dual
eligibles") who were not automatically
enrolled in a Part D plan will be able to
enroll between May 15 and Nov 15.

If you were eligible to enroll before May 15 and did not enroll, your premium cost will go up at least 1% per month for every month after May 2006 that you have delayed enrolling in a Part D plan. For a \$30 monthly premium, a 10-month delay adds 10% to become \$33. It adds up.

People who become eligible for Medicare after May 2006 can enroll in a Medicare Rx plan without penalty if they enroll when they first become eligible. In

continued on page 37

Calmly Doing Your Will

Getting around to writing or updating a will is one of those things that always seems to wind up at the bottom of our "to-do" list.

ometimes, however, we get a nudge that makes us act. A far happier sense of urgency about preparing a will is vacation planning. A long-awaited vacation easily becomes the motivation to get all kinds of things in order. We know nothing bad will happen on vacation, but still the nudge is there to buy trip insurance and to take the time to write or update a will.

Even unexpected news from a physician can cause us to take the first steps toward making those long-delayed estate-planning decisions.

Urgency is good and bad

Following through on a mental nudge is a good thing, but acting on nudges has its downside too. Poor or faulty decisions are a common result when we are hurried.



Your friends in the Planned Giving department at the National MS Society urge you to set aside a block of time and find the mental tranquility that will yield sound estate-planning decisions.

For answers to many of your estate planning questions visit the National Multiple Sclerosis Society on the Web. Go to www.nationalmssociety.org. Click on "Get Involved," then on "Guide to Giving." Or call the national Planned Giving department at 1-800-923-7727.

2006 MS Walk Volunteers

Thank you to all of the volunteers who served at the 2006 MS Walk

April Adams

Stacey Anderson

Doug Anderson

George Antonsen

Brecken Arnold

Brooke Baranowski

Ruth Baxter

Daniel Blatter

Christin Bott

Jocelyn & Joe Boud

Kacey Bowles

Alec Bowman

Jake Bowman

Max Bowman

Ryan Braski

Travis Brewster

Scott Bringhurst

Christine Burgess

Joshua Byrd

Russ Campbell

Cynthia Chadwick

Dana Condie

Karen Condie

Michael Cook

Shayla Craig

Evelin Damian

Azia Dansie

Tonia, Nikita, & Demarcus Davis

Aaron Doehler

Jill & Travis Drown

Ashley Earl

Julie Earl

Bev Folsom

Daryl & Barbara Frame

Jeff Frame

Melodie Gav

Donalyn Germundson

Jenn Gonnelly

Abbi Green

Jewly & Murray Harris

Cecil Hedger

Sharon Heightman

Amanda Herbert

Connie & Craig Hinerman

Sherrie Hirst

Hans Holland

Heather Horn

Nellene Howard

Charese Jamison

Richard Jenkins

Kesli & Richard Jensen

Versell Johnson

Rich & Shirley Knickerbocker

Dale Kovalczyk

Torie Kowslowsky

Jeremy Kraus

Kevin & Jennifer Kruse

Rene & Angelina Kump

Liz Leyda

Andrew Madden

Dennis Marcus

Brenna Marron

David Martini

David Martini

Angela McClure

Truly Memmott

Sharon Mintiloglitis

Charlie & Michelle Morgan

Shummy Muse

Suzi & Stew Olsen

Rachel & Whitney Olsen

Nubia Pena

Dawn & Ivan Perry

Jessica Peterson

Stephanie Peterson

Bruce Peterson

Jason Phillips

Vasori i illilips

Mary Rappleyi

Rachel Ringheimer

Nick Robbins

Christal Ruehl

Aliitasi Saumani

Jill Sawaya

Kirsten Schoetz

Joyce Shelton

Gary Shelton

Jaclyn Sides

Brenda Spearman

Lori Stevens

Katherine Stevens

Ashley Stolworthy

Jacque Stonehocker

Trevor Thinnes

Sarah Timms

Viliamu Touli

Cheryl & Heidi Vincent

Marilyn Voravong

Lesli Wallace

Heidi Wallick

Leslie Ward

Brenda Wiener

Cody Wilcox

Kari Willis

Dwayne & Jaron Woolley

Glade Hamilton and the

Cedar City MS Walk

Volunteers

Frank Roskelley and the

Ogden MS Walk

Volunteers

Liz Davis and the Provo MS

Walk Volunteers

Joe Stallings and the St.

George MS Walk

Volunteers

Verney Heeney and the Vernal MS Walk

Volunteers

SUMMER2006

2006 MS 150 Bike Tour Volunteers

Thank you to all of the volunteers who served at the 2006 MS 150 Bike Tour

Laurie Adams Jeremy Adams Craig Adams Tamara J Adams Amber Adams BreeAnn Allred Jessica Allred Samuel Allred Lisa Andersen Alex Anderson Ariella Anderson Arie Anderson Crystal Anderson Nikki Archibald Gerri Archuleta Jammie Argyle Gina Atalah Andy Averett Carla Averett Jason Averett Deb Badger Jackie Baird Edward Baker Lee Ballentyne Julie Ban Cheryl, Thomas, & Meghan Banks Launa Barker Kalai Barrow Karen Barton Katie Bastron Diana Bateman Ruth & Adam Baxter Sara Baza Angela Benedetto Shawn Benvegnu Rylee Berglund

Sara Bingham Richard David Bishop Andrew Bishop Jessica Black **Daniel & Catherine** Blakemore Spenser Blauer **Christin Bott** Norman Bowers Tiffany Braaksma Lynn Bradley Lana Braegger Tammy Braegger Jeremy Brasfield Jacalyn Brenchley Linda Brigance Stacia Brown Robert Brown Brianna Browning Laura Browning Bianna Browning Ellie & Peter Brownstein **Brent Bryan** Rhonda Bulcher Rob Burr Nate Burridge **Trenton Bute Travis Bute** Ashley Bute Laurie Bute Michelle Byrd Joshua Byrd Kylie Cahoon Brighton Callaghan Michelle Callister Adrie Campbell Mel Campbell **Annette Carhart** Cindy Castro

Cynthia Chadwick Lynn Chandler Mark Chapman Noelle Christensen Tyler Christensen **Brent Christensen** Teresa Christensen Michael Christensen Brenda Christensen Kimberly Christenson Tonianne Christenson Linda Christenson Rick Christenson Lorraine Cole Quinn Coleman Vonda Collins Jennie Conder Alan Condrat Bill Connell Sherri Cotton Scott Critchlow Megan Crump **Dwight Curry** Heidi Dangerfield Tonia, Nikita, & **Demarcus Davis Andrew Davis** Rachel Davis Michelle Dean Kathleen Dean Brenda Dean Bobbi Degrado Theresa DeGraw Tammy DeGraw Andrea Deming Danielle Denne Cathy Denton Josh Dewitt

Chris Draper Jackson Druce Cheryl Duncan Jean, Travis, Jesse, & Madison Dunn Korbin Durham Neomi Dyal Julie Earl Ashley Earl Darek Eggleston Ella Eldredge Janeen Elkins Christine Ellingson Tanner Elton Luke Embly Debbie Empey Morgan Empey Teri Erikson Tanna Ernest Rex Estes Susan Everett Katie Evertsen Zak Evertsen **David Eyring Taylor Eyring** Michelle Eyring Julie Eyring Cauley Family Gibbs Family Farrell Family Wilker Family Fulghum Family Jackie & Timothy Fehr JoAnne Ferranti Heather Fischer Megan Fluckinger **Bob Fowler** Jade Pearl Frost Keith Fullenkamp

Derek Berglund

Kelley Bible

Tammy Dickerson

2006 MS 150 Bike Tour Volunteers

Dan & Mary Fullerton
Furano Family
Amory Gardner
Mike Gardner
Maurine Geiger
Sharon German
Amy Gibbs
Lyn Gibbs
Wade Gibbs
Allison, Bryce, & Taylor
Gibbs
Cindy Gillman

Jolene Grant
Stu Grater
Howard Gravelle
Margaret Graves
Marian Graves
Nathan Grigg
Brad Grover
Kathy Hale
Stephen Hambor
Whitney Hansen
Walter Hanssen

Ben Harris DeAnn Haslam Emily Haslam JoAnne Hawe Rachel Hawker

Vicki Harder

Jay Hawley Tressa Heil Keith Heil

Jamie Helgesen Erik Helgesen Febie Hermansvah

Febie Hermansyah Sandra Hill

Joshua Hill

Teresa & Joseph Holm

Hayley Hortin

Katherine Humphreys Jacobs Humphreys Emma Humphreys Sarah Humphreys Malia Humphreys Melissa Humphreys Michael Humphreys Heidi Jackson

Bryant Jakeman Charese Jamison

Crystal Janke Kari Jaramillo

Jenny Jasperson Richard Jenkins Shelly Jensen

Karen Jensen Kyle Jensen Debbe Jones

Sally Jones Kelly & April Jones Lauren Jones

Jerrynah Khanhnara Souyanthong Khanhnara Sharlene Kierstead

Robert Kierstead Heather Kimber Jason Kimber

Debbie Kimose Greg Kordas Dale Kovalczyk

Torie Kowslowsky Jeremy Kraus

Jeremy Kraus
Jennifer Kruse
Bob Kuster

Thu Lam
Ron Larsen
Tv Larsen

Beverly & Jamie

Larsen

Diana Jean Law
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Becky Lindley
Mary Lindsay
Kate Lingwall
Larry Lloyd
Lorraine Long

Tammy Long

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Doug Morgan
John Morgan
Mott Mozingo

Matt Mozingo Olivia Namdar Shawnee Nash

Liz Nebeker Steven Nelson Rebecca Ng

Ingrid Niesen Brvan Olchek

Rachel & Suzi Olsen

Whitney Olsen Valarie Olsen Stuart Olsen Charlie Olsen Suzi Olsen Rachel Olsen Linda Olson

Jen Pace Wynette Pace Jennifer Pardue Brenda Park Jay Partridge

Dan Paskett

Randel & Debra Patten Carolyn Pease Andrea Perez Anthony Perez Rov Perez

Espie Perez
Dawn Perry
Bruce Peterson

John Pettijohn Jaclynn Pettingill Michael Pettit Krista Phillips

Joshua Pineauit Misty Presser Jeff Presser

Kaden Price Kaylee Price

Kate Quan Matt Rager

Tyler Raines Leticia Ramirez

Mary Rappleyi
Louise Rausch

Steve Reid Suzanne Ren

Olson & Sutton Residence

Cami Rimington
Nick Robbins
Leissa Roberts
Tyler Roberts
John Rodriguez
Noreen Roeca

Danny Rogers Steve Roll Ron Romero Jim Rosetto

Deb Roskelley Mark & David Sarette

Employees of Saturn of Ogden Lisa Schmidt Barbara Schneiter

Kirsten Schoetz Scott & Cathy Schwaelger Dixie

Lee Schwartz James and Cyrstal Scott

Lori Scott Matt Scott Susanne Scott Jenna Seeley

2006 MS 150 Bike Tour Volunteers

Jina Severisnsen Launie Severisnsen Robert Severisnsen Beva Shelby **Gary Shelton** Ryan Shelton Richard Simmons Judy Smith Andrew Smith Ken Smith Andrew Smith Mark Sosette Carlene Spaulding Shauna Springer Craig Stahl Rebecca & Michael **Stallings**

Joshua Stevens

Shelley Stoker Mykelle Stokes Ashley Stolworthy Jacque Stonehocker Jeff Stowell Carvn Summers Steve Summers Rachel Sumner Kaitlyn Sumner Sallie & Lemuel Sutton Lemuel Sutton Gayna Svee Dee Taylor Lavcee Taylor Team Red Ex Ray Thacker Spring Theisen Chambre Thomas

Jenni Thompson Kim Thompson JoAnne Thompson Susie Turner Jay Turner Jacilyn Udy Ladd Udv Lisa Unq Todd Vanburen Amir Varedi Lammert Veenstra Christopher Virgin Marilyn Voravong JJ Wallace Heidi Wallick Bryce Ward **Jay Waters** Nicole Welch Lynette Wescott

Don Wescott Sam Western Shawn Western Stephen Western Mary White Vickie Whiting Clay, Wendy, & Clinton Wilker Lesle Wilkinson Davis Lane Willie Stefanie Wilson Treva Wolfley Kevin Wood **Taylor Wyatt** Karen Wyatt Noreen Wynn Rhonda P. Yorgason Phil Yorgason Bessie Zobell

Thank you to all of the members of the 2006 MS Walk Committee

Robert Clark Tonia Davis Meta Hutchinson Kim Antonesen Sandy Pearce Pete Taylor Jennifer Kruse Sandra Ishii-Johnson Frank Roskelley

EJ McCaffrey Angelo Papastamos Melissa Adamson Greg Nicholes



Thank you to all of the members of the 2006 MS 150 Bike Tour Committee



Gina Atalah Peter Ballantine Skylere Bingham Pat Burrus Guy Curtis

Susan Everett
Raleigh Fehr
Garrett Harding
Graydon Jensen
Kevin Kruse

Dennis Marcus Mike McHugh Jeff Pease Mike Renlund Frank Roskelly Pete Taylor

MEMORIALS & TRIBUTES

MEMORIAL

Ginnie Cragun

By Ruben Gottardi & Cassandra Stuercke Anonymous Gift

Al Cortez

By Dr. & Mrs. Charles Behrens

Randy Olsen

By Leslie Richards

Shirley Callister Barton

Anonymous Gift

William Charles Barney

By Mary Behrens

Aldo Aronie

By Rob Camden

Alice Forbes

By CG and Kathy Caruthers

Joseph Lachica

By CG and Kathy Caruthers

Ron Zabriskie

By CG and Kathy Caruthers

Annie Papp

By Betty Smith

Harold Roberts

By Betty and Chad Smith

Darren Thompson

By Maxine Marcusen and Family By Bob and Marilynn Olson

By Sharon Thompson

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, their families, and friends. I (we) wish to support the Utah State Chapter with a gift of \$ Name:_____ Method of Payment: ☐ Check enclosed. (Make checks payable to the National MS Society) Phone Number:______ □ VISA □ MasterCard □ Amex Name of Cardholder: E-mail: ☐ Wedding/Anniversary: ☐ Birthday: Account #_____ ☐ In memory of: ☐ In honor of: Exp. Date:_____ Signature: Enclosed is my company's matching gift from: ☐ Please send notice of this gift to: ☐ 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.

Podcast or Webcast?

Your Choice with MS Learn Online

S Learn Online is a webcast series hosted by experts on a wide variety of topics related to MS. New programs will now also be available as podcasts.

A podcast is an audio file that can be downloaded to a computer, imported to an MP3 player such as an iPod, or burned to a CD. You'll be able to listen

to a program at any time or place or share it with a group on a CD player.

The first MS Learn Online podcast programs are "Starting with the Basics" and "Complementary & Alternative Medicine: Integrating Unconventional Approaches."

To download, go to www.nationalmssociety.org/podcast. The Web page includes how-to instructions.

Exacerbation? Relapse? Attack? Episode? Flare?

by Dr. Lael Stone, Mellen Center for Multiple Sclerosis, The Cleveland Clinic

xacerbation, relapse, attack, episode, or flare-up, in MS, all these words refer to exactly the same thing: all mean a period of sudden worsening, with symptoms that last 24 hours or more.

Exacerbations are characteristic of three of the four clinical courses in MS—relapsing-remitting, secondary-progressive, and progressive-relapsing.

The fourth course is called primary-progressive. These people will have the same good-day, bad-day phenomena that many people with MS and, indeed, many healthy individuals experience. But they don't have a sudden worsening of symptoms, lasting longer than 48 hours. Instead they say that over several years or

maybe even decades something has gradually worsened. For example a mild foot drop increased to the point where now the foot is slapping on the ground with every step.

Silent attacks and clinical attacks

Many MS attacks are silent or "subclinical"; that is to say, they are only seen on MRI of the brain or spinal cord. These people appear to be stable and don't notice any unusual symptoms but when we take an MRI we can see that they have more lesions present.

Both clinical and silent attacks can be reduced and/or shortened by taking one of the disease-modifying medications.

Tysabri Returns to the Market with Tighter Controls

Administration (FDA) approved Tysabri's return to market for people with relapsing MS, despite its risk of causing PML, a potentially fatal disease. To minimize this risk, those wishing to use the drug will be required to participate in a rigorous monitoring program and may receive treatment only at authorized infusion centers. The drug became available in July.

Tysabri (natalizumab), which is given as a monthly IV infusion, was withdrawn in 2005 by Biogen Idec and Elan Pharmaceuticals, Inc., after three people, among the 3,000 who had been taking the drug in clinical trials, developed PML (progressive multifocal leukoencephalopathy). Two of them died.

But, last March at a special hearing a Food and Drug Administration Advisory Committee evaluated clinical trial data suggesting that Tysabri may have twice the efficacy rate of other available MS treatments. After reviewing additional safety studies, and the manufacturer's proposed risk management plan, the panel recommended the drug be returned to market for the treatment of relapsing MS, a recommendation that has now been formally approved by the full regulatory board of the FDA. The approval, however, is linked to a strict mandatory registration and monitoring program for patients and their prescribing physicians. The drug also carries a "black box" warning describing the risks.

A new option added to our list

"It's important that people with relapsing MS now have a new treatment option," said John R. Richert, MD, vice president of Research and Clinical Programs for the Society.

"Because of the risk of PML," Dr. Richert continued, "the FDA is recommending that Tysabri be given to people who have not responded adequately to, or cannot tolerate, other treatments for MS." It has ben left to individual physicians and patients to define 'inadequate response' and what it means to be 'unable to tolerate' other therapies.

Patients with MS are already wrestling with the pros and cons of turning to Tysabri as a treatment option. James Blog, a consultant from Huntington, NY, had been on Tysabri for 18 months, and was actually in the midst of an infusion, when Tysabri was withdrawn from the market last year. Says Jim, "I am worried about it. I think if I go back on, I am taking X number of risks, which is why I want to see what precautions they'll take to protect patients."

Advises Dr. Richert, "We believe that the mandatory patient registry and the designated post-marketing observational study will help clarify the potential benefits and risks of this new therapy for people with MS."

■ Tysabri

— continued from previous page

Tysabri: a closer look

Who should take Tysabri?

- The FDA has approved Tysabri as a **monotherapy** for people with relapsing forms of MS who do not have a compromised immune system or who are not taking other drugs that suppress or modulate the immune system such as Avonex, Betaseron, Copaxone, Rebif, Novantrone, or monthly IV steroids.

How is Tysabri given?

- Tysabri is given every four weeks by intravenous infusion, at an authorized infusion center.

How will safety risks be managed with Tysabri?

- In order to use Tysabri, physicians and patients will be registered in a mandatory program called TOUCH. Prescribers and infusion personnel will receive special training in recognizing early signs of PML. Information about the risks and potential side effects will be given to each patient. Before every infusion, medical staff and patients will complete a checklist to identify any new neurological signs or symptoms that require evaluation by a physician.
- Patients on Tysabri should be evaluated by the prescribing physician 3 and 6 months after the first infusion and every 6 months thereafter.

Is Tysabri available everywhere?

Starting in July, Biogen and Elan began supplying Tysari to authorized infusion sites and they are planning to train health-care professionals and register new sites around the country. For information about the location of these sites, contact Biogen Idec's MS Active Source.

What is the cost of Tysabri?

- According to the company's Web site, Tysabri will cost \$2,184.62 per vial. It is administered 13 times per years for an estimated cost of \$28,400. Biogen Idec and Elan advise that they are committed to making Tysabri accessible to appropriate patients who may benefit from therapy. To achieve this goal, programs have been developed to assist patients who are uninsured or who require financial assistance. The Society will work with the companies to ensure they pursue this commitment.

Will insurance cover the cost?

- There may be a lag time before the drug is included in private health plans. Prior authorization will probably be necessary for most health plans.
- Tysabri is expected to be covered by Medicare Part B because it is given at a medical facility.
- People with Medicaid should check with their state program. There may be a delay before Tysabri is included in the Medicaid preferred drug list.

More information is available: On the Society Web site at www.nationalmssociety.org/tysabri or call the chapter at 1-800-FIGHT-MS (1-800-344-867)

From the FDA at www.fda.gov/cder/drug/infopage/natalizumab/default.htm

From Biogen Idec's Active Source at www.biogenidec.com or call 800-456-2255.

Hit the Road, Jack

by Dana Bard

ast year Pat and I headed off on a two-week road trip. I had wanted to spend the whole time camping under the stars, but Pat proposed a more MS-friendly plan that involved dividing our time among a suburban motel with a pool, a bed & breakfast in a small town, and two campgrounds—all of them accessible. Camping the whole time would have been a bit much for me, and the plan we made wound up providing us exciting variety.

Based on the success of last year's trip, we put together a list of things to remember for this year's outing.

Driving tips

- **Take turns driving.** If you have lots of energy in the morning, let your partner take the wheel in the afternoon.
- Keep travel time to a minimum. Choose numerous destinations, no more than six hours apart, and plan to stay more than a day whenever possible.
- Check the weather. If it's going to be hot, make sure your vehicle has adequate AC. Early summer road trips are usually cooler than July or August.
- Keep a cooler with ice and a towel in the backseat. Wrap the towel around your shoulders if you get overheated. Lots of bottled water or one of the cooling products are also a good idea.
- The rest stop is your friend. Don't be shy! Pull over when you see a restroom sign, even at the slightest "urging."

Make sure your destination is accessible

"Accessible" is a word that seems to mean as many things to as many people as "multiple sclerosis." Know where



you're going, and call ahead. Ask specific questions:

- Are the trails dirt, rock, or paved?
- How wide is the door into the bathroom and stalls?
- How high is the bed?
- Are there ramps for raised areas, or just steps?

Take a vacation from your vacation

There's nothing worse than going back to work the day after you've returned home from a long trip. Plan to get home on a Thursday night or early Friday morning, give yourself a full three-day weekend before going back to the grind.

Last year, Dana Bard wrote about virtual camping. Go to www.nationalmssociety.org/
IMSJune05-SeaToSea.asp for the article, which includes links to accessible travel resources on the Web.

Dana also recommends Candy
Harrington's *Barrier-Free Travel: A Nuts And Bolts Guide For Wheelers And Slow Walkers* and *There is Room at the Inn: Inns and B&Bs for Wheelers and Slow Walkers.* (Both published by Demos Medical Publishing: 800-532-8663; www.demosmedpub.com.)

Managing MS

Tame MS with a Better Diet

You've just been diagnosed and you've already been told: "Change your diet!" You want to be as healthy as you can—and your diet is something you can control.

he Google search engine offers 2,500 **million** websites on "diet and multiple sclerosis"—many predicting doom if a person with MS fails to eliminate all dairy products, animal fat, meat, sugar in any form, gluten, "allergens"—the list goes on.

Ouch!

Who has the skinny?

The National MS Society respectfully suggests that—based on all evidence available to date—there is no scientific reason to suspect that burgers and fries cause MS or make MS worse. There is data suggesting that smoking and low vitamin D levels may affect susceptibility to MS.

There is also scientific reason to suspect that saturated fats (burgers and fries) increase the risk of other serious ills. In fact, a high fiber, low-fat diet is recommended by a host of medical advisors for everyone. Eating well means enjoying "five a day"—five servings of fruits or vegetables, limiting (not eliminating) certain foods, and balancing calories and physical activity.



Is that all there is?

Not quite. There is substantial data that people with relapsing forms of MS benefit from faithfully taking one of the approved disease modifying drugs.

Some data also suggests that people with MS benefit from a diet low in animal fat and higher in PUFAs (polyunsaturated fatty acids) specifically Omega-6 (found in sesame, sunflower, safflower, and evening primrose oils) and Omega-3 (found in ocean fish and flax-seed oils.)

According to Dr. Allen Bowling of the Rocky Mountain MS Center, who directs a Web site on complementary therapy in MS*, making changes in the types of fats eaten—in combination with a disease-modifying drug if indicated—may be worth considering for those who want a dietary approach. But taking PUFA supplements should be discussed with a health-care professional, especially if you use anticoagulant medication, have

WELLNESS PROGRAMS

■ Tame MS with a Better Diet

— continued from previous page

diabetes, or may need surgery. The data showing PUFA benefits in MS are "suggestive but limited," he says.

Healthy eating isn't boring but change is the pits

Changing eating habits is hard. It takes time, imagination, and support. But it can be done. For starters, type "low fat fun" on your search engine and experiment. Bon appetit!

*For more information on diet and other alternatives, see www.MS-CAM.org or Dr. Bowling's book, Alternative Medicine and Multiple Sclerosis, Demos, 2001.

■ Next Medicare Part D Enrollment

— continued from page 25

addition, anyone who wants to switch to a different Rx plan may do so between November 15 and December 31 of each year. The new plan would take effect January 1 of the following year.

The Society has a one-stop list of resources at

www.nationalmssociety.org/ medicare. There are links to your State Health Insurance Assistance Program and to Medicare's Web site where you can Compare Medicare Prescription Drug Plans.

For help, call us at 1-800-FIGHT-MS (1-800-344-4867).

Physical Health

Please contact Chelsey Butchereit or 800-FIGHT MS and select option 1 for more information.

Physical Therapy

University of Utah
Salt Lake City
Mon, Wed, Fri
8:00 am - 12:00 pm

Cost: \$20/month

Health South

Sandy Tuesday or Thursday 11:00 am – 12:00 pm Cost: \$20/month

Orem Sports Medicine

Orem Tuesday 10:00 am – 12:00 pm Cost: \$20/month

Aquatics

Steiner West

855 W. California Ave
West Valley City
Tuesdays and Thursdays
5:00 pm - 6:00 pm
Cost: \$22.50/15-class punch pass

Roy Recreation Complex

2150 W. 4700 S.

Roy

Mondays and Thursdays
6:00 pm – 6:45 pm

Cost: \$10/10-class punch pass

Self Help Groups

Before you choose a group, ask yourself what atmosphere you feel most 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 are unable to find a group to meet your needs, contact the chapter to start your own.

Northern Utah Ogden

2nd Tuesday 11:00 am Roy Library 1950 W 4800 S Barbara Schneiter 731-7088 Joyce McCall 547-9840

Logan

3rd Saturday 1:00 – 3:00 pm Independent Living Center 1095 N Main Street Sally Anderson 751-8270 Monica Eames 245-4919

Salt Lake Area Bountiful

Scrapaholics 3rd Wednesday 6:30 - 8:30 pm Davis County Library 725 S. Main Street Julie Doherty 951-1507 Sandi Hill 543-1915

Salt Lake City

Child or Teen w/MS 2nd Saturday 10:00 am Call for Location Lynne Myhre 832-0173

Beyond MS

Wednesdays 7:00 pm Utah State Chapter 6364 S Highland Dr Beverly Trabanino 280-4480 Cheryl Hyman 886-0256

Knowledge is Power

3rd Saturday 10:30 am Murray City Library 166 E 5300 S Cheryl Hyman 886-0256 Heather Horne 262-5967

Riverton

3rd Thursday 4:00 pm Intel Corporation 3740 W 13400 S #116 Lori Stevens 580-7885

West Valley Area

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

Central Utah

Contact the chapter to begin your own group.

Eastern Utah Price

1st Tuesday 7:30 pm Health Department 28 S 100 E Danny Velasquez 435-637-0712

Vernal

3rd Thursday 6:30 – 7:30 pm Vernal City Offices Vernie Heeney 435-789-1903

Southern Utah St. George

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

Cedar City

3rd Saturday 11:00 am Chamber of Commerce (Enter west doors) Linda Lohrengel 435-586-8001

Please join us for dinner & an informative evening!



KNOWLEDGE IS POWER- OGDEN

September 21st with Tamara Myers, PA-C Jasoh's-4590 S Harrison Blvd, 6-9PM

SUCCESS with MS - PROVO

September 27th with Pam Vincent, MD Magelby's Grill- 4801 N University Avenue 6-9PM

MS BASICS- TOOELE October 5th with Emily Kriech, PA-C The Eagles Nest-Tooele Army Depot 6-9 PM

CHOICES & CHANGES- SLC
October 19th with Sheri Rosenblatt, PA-C Red Robin- 316 E Winchester Street (Fashion Place) 6-9PM

MS in Balance complimentary seminars with dinner provided are for people living with MS, their families, friends & caregivers to provide information & insights that can help keep MS in Balance!

RSVP Toll Free 1-877-329-8327

Please state which programs you will be attending





You're invited to learn the facts about MS





You need accurate information to make choices for your life. A mulitple sclerosis (MS) specialist will take the time to describe and explain what MS really is, a range of treatment options and what you can do to live well.

So whether you are recently diagnosed or have had MS for a while, take advantage of the information and support a live event can offer.

Advances in the Treatment of Multiple Sclerosis

September 7, 2006
Registration: 5:30 PM
Seminar: 6:30 PM-8:30 PM

Jordan Commons Megaplex Theatres

35 East 9270 South • Sandy, UT
Complimentary dinner buffet will be served
Complimentary parking available

Featured Speakers:

John F. Foley, MD Kara Menning, NP Molly Roy, PA

And hear inspiring stories from a patient advocate

Code: N



Call now to register now for this free program!

1-866-955-9999 or visit online www.MSActiveSource.com



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