

# MSCONNECTION

MOVING TOWARD A WORLD FREE OF MS | SPRING • 2010



## CLINICAL TRIALS IN MULTIPLE SCLEROSIS

ANDREA WHITE, PHD, UTAH STATE CHAPTER RESEARCH ADVOCATE

Multiple Sclerosis research is progressing at a remarkable rate. There are more potential therapies in the research pipeline than at any other time in history. These research advances could not occur without individuals willing to participate in clinical trials. In Utah alone there are nearly twenty clinical trials in progress, many of which are part of larger studies taking place at other sites.

People participate in clinical trials for various reasons. Some participants in clinical trials want the opportunity to play a more active role in their own health care. Others wish to gain access to new research treatments before they are widely available or to help others by contributing to medical research. Other individuals elect to participate in clinical research to gain access to sought after specialists or to obtain medical care not covered by their insurance plans.

Each study has specific requirements for those wishing to enroll. Generally, trial participants will need to reside close to the research facility, have a diagnosis of MS, meet the study guidelines of age, sex, level of disability, and duration of disease, and the patient must be able to understand the risks of participation and be able to give consent to participate.

**"TRIALS" CONTINUED ON PAGE 3**

Potential therapies begin in the research facilities.

### UTAHTRIALS

More information at:

- [nationalMSSociety.org](http://nationalMSSociety.org)
- [cureMSUtah.org](http://cureMSUtah.org)
- [clinicaltrials.gov](http://clinicaltrials.gov)

### INSIDE THIS ISSUE



Summer Programs  
PAGE 6



Chapter Calendar  
PAGE 11



Research Update  
PAGE 14



Bike MS with MS  
PAGE 16



**National  
Multiple Sclerosis  
Society**  
Utah State  
Chapter

# join us!



Carolyn,  
living with RRMS  
since 2002

## Taking Control: Managing MS Symptoms

You may have good hearing, but are you really “listening” to your body? It’s critical for patients with relapsing MS to pay close attention to their health and monitor themselves for any potential symptoms. This educational session will provide you with helpful tips on how to “listen” to your body and take control of your MS.



### Program Details

**Thursday, May 20, 2010**

**Radisson Hotel**

215 West South Temple

Salt Lake City, UT

6:15 PM Registration

6:30 PM Program

Dinner

### Featured Speaker(s)

**Randall T. Schapiro, M.D.**

Director, The Schapiro Center for Multiple Sclerosis  
at The Minneapolis Clinic of Neurology  
and Clinical Professor of Neurology

Program sponsored by



Services sponsored by



## Take Action & Register Today!

Call toll free 1-800-292-6204

Use Meeting ID#EZ2511371

Pfizer respects your privacy. We require your RSVP for headcount only. When you RSVP, it is not necessary to provide your name; you should simply identify yourself as a consumer who is accepting the invitation. Pfizer's educational programs for consumers are conducted in accordance with the same high ethical standards that we apply to our programs for healthcare professionals. The sole purpose of consumer programs is to educate you on general healthcare issues. Pfizer cannot provide diagnosis, treatment or other medical advice to you. If you have any medical questions regarding your own health, diagnosis or treatment, please consult your healthcare provider.

MS LifeLines is an educational support service for people living with MS and their families. MS LifeLines and MS LifeLines Ambassadors are sponsored by EMD Serono, Inc. and Pfizer Inc. MS LifeLines is a registered trademark of EMD Serono, Inc. or its affiliates. MS In Balance Your Life In Full is a service mark of EMD Serono, Inc. or its affiliates. © 2009 EMD Serono, Inc. All rights reserved. XX-XXXX X/09 Printed in the USA

If participating in a clinical trial is something you are thinking about, there are some key questions to ask the study investigators before making that final decision. After the questions have been answered, you may want to discuss the study further with your neurologist and your family.

What is the purpose of the study? Clinical trials might be designed to assess the safety of a new treatment, to determine if an additional treatment enhances an existing therapy, or to examine a new route of delivery for a drug. Other trials might be focused on rehabilitation or treatment of secondary symptoms in MS. Knowing the purpose will help you assess the risk involved and the potential benefits.

What kinds of tests and treatments are involved? The investigators should explain exactly what procedures will be followed during the trial, and you should understand the risks and discomforts associated with each one.

Who will pay for the experimental treatment? In some trials, any experimental or research-related expense is covered by the study sponsor. However, it is also common for many of these expenses to be billed to insurance. You should understand whether your insurance will be billed and whether the costs will be covered.

Will I be reimbursed for other expenses? It is typical to receive some compensation for the time and travel expenses you incur as a research participant, though this is not always true.

Clinical trials across the country are bringing new hope for oral drugs, better options for people with progressive MS, and novel approaches to alleviating symptoms. ■

**800-344-4867**

## **PUBLICATION OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY UTAH STATE CHAPTER**

Studies show that early and ongoing treatment with an FDA-approved therapy can reduce future disease activity and improve quality of life for many people with multiple sclerosis. Talk to your health care professional or contact the National MS Society at [nationalMSSociety.org](http://nationalMSSociety.org) or 1-800-344-4867 to learn about ways to help manage multiple sclerosis and about current research that may one day reveal a cure.

The National Multiple Sclerosis Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The National Multiple Sclerosis 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 Multiple Sclerosis Society is dedicated to ending the devastating effects of MS.

© 2010 National Multiple Sclerosis Society, Utah State Chapter

## UTAH CHAPTER STAFF

**Chapter President** • Annette Royle

**Executive Coordinator** • Martha King

**Director of Client Programs & Services** •  
DeeDee Fox

**Programs & Services Manager** •  
Rachael Lyon, MSW

**Programs & Advocacy Coordinator** •  
Brook Osterland, MPA

**Direct Services Manager** •  
Clare Wright, LCSW, M.Ed., TRT

**Director of Team Fundraising &  
Sponsorship** • Becky Woolley

**Director of Individual & Foundation  
Giving** • Rachel Taylor

**Events Manager** • Tara Bradshaw

**Development Manager** • Ryan Romeike

**Marketing Development & Volunteer  
Coordinator** • Seth Bowers

**Director of Finance** • Ron Clem

**Database Manager** • Carmen Burson

**Administrative Associate** • Kim Gallegos

National Multiple Sclerosis Society  
Utah State Chapter  
6364 South Highland Drive Suite #101  
Salt Lake City, UT 84121

800-344-4867  
cureMSUtah.org

## UTAH STATE CHAPTER 2010 BOARD OF TRUSTEES

**Chair of the Board** • Ann Sasich

### Board of Trustees

Richard Baringer, M.D.

Richard Flint

John Foley, M.D.

Jay Gurmankin

Bob Harmon

Cecil Hedger, Secretary

Jeana Hutchings

Safia Keller

Cindy Kindred

Nicole Lengel, Treasurer

Philip McCarthy

Jordan Needles

Todd Oldroyd

Irene Petrogeorge

Colleen Roberts

John Rose, M.D.

Maggie St. Claire

Sheila Steiner

**Chapter President and Ex Officio Member  
of Board** • Annette Royle

If you would like to nominate someone to serve on the Board of Trustees, nomination forms are available under the board list on our web site: [cureMSUtah.org](http://cureMSUtah.org).

## PRESIDENT'S MESSAGE

### ANNETTE ROYLE, CHAPTER PRESIDENT

Each spring our office starts to bustle with Walk MS and Bike MS paraphernalia. Everything from posters, T-shirts, bananas and yes – donations – are coming through the front door. I'm so grateful for the more than 8,500 fundraisers we have with Walk MS and Bike MS that help us raise nearly 80% of our budget. Their effort is what allows us to provide support to so many affected by MS.

The real joy in my work is when I have the chance to meet with those we serve. Walk MS 2010 has given me that opportunity, and it's reminded me just how important the programs and services we offer are. I'm amazed by how many people are participating in Walk MS for the first time – because this is the year they were diagnosed. For these families I know our newly diagnosed programs are helping to orient them through this initial stage of their diagnosis. Programs like Knowledge is Power, information like the latest news on disease modifying therapies, and connections to resources that provide support in our community.

I've also met so many families who participate in Walk MS in honor of not just one, but multiple family members with MS. This is when I'm grateful for the lead role the Society plays in funding research to find a cure. It's no surprise that with the breadth of family history in our state that Dr. John Rose at the University of Utah is playing a key role in conducting genetic research in MS. Research which has now identified at least 35 genes connected to multiple sclerosis.

I also was introduced to two of the most energetic people with MS I've ever met. Kaylee and Sydney were both diagnosed with MS at the age of 8 and are now best friends who ran in and out of our Walk MS crowd hand-in-hand. The Society's Pediatric MS Centers of Excellence are helping us to better understand and treat children with MS every day. With the momentum we have in research, and the support we have from our donors, advocates and volunteers, I can't help but hope that soon we will see our last generation of MS. Thank you to all who have Joined the Movement and are doing what you can to make a difference.

*Annette Royle*



**Chapter President Annette Royle (right) with Bob Welker, overall Fit MS winner and team captain of Bob's Army.**

## OUTDOOR ADVENTURE OPPORTUNITIES IN UTAH SUMMER PROGRAMS FOR THE WHOLE FAMILY



It is almost summer, which means it is time to enjoy the weather and the outdoors!

There are recreational organizations across the state geared towards families and all levels of ability. You can take advantage of many trips and activities offered by these resources in your community including river rafting, horseback riding, rock climbing, ropes courses, and more!

Here are a few organizations that offer recreational services for all ability levels.

### **SPLORE**

Splore is a Utah based non-profit organization that promotes empowering experiences in an active friendly world through affordable, customized, inclusive recreation and education

programs for people of all abilities.

Website: [splore.org](http://splore.org)  
Phone: 801-484-4128

### **NATIONAL ABILITY CENTER (NAC)**

The National Ability Center is committed to the development of lifetime skills for people of all ages and abilities by providing affordable outdoor sports and recreational experiences in a nurturing environment.

Website: [discovernac.org](http://discovernac.org)  
Phone: 435-649-3991

### **THE STABLE PLACE**

The Stable Place works to create an environment where horses and people can help heal each other, regardless of physical, mental, or emotional challenges. By connecting people and horses, The Stable Place provides opportunities to build trust, find hope, and improve the quality of life for people and horses alike.

Website: [thestableplaceslc.com](http://thestableplaceslc.com)  
Phone: 801-860-3906

### **CAMP KOSTOPULOS**

Since 1967 the Kostopulos Dream Foundation has been dedicated to

improving the lives of people with disabilities through the medium of recreation and leisure education.

Website: [campk.org](http://campk.org)  
Phone: 801-582-0700

### **COMMON GROUND**

Common Ground Outdoor Adventures' mission is to provide life-enhancing outdoor recreational opportunities for youth and adults with disabilities. They provide adaptive equipment and support, which enable people with disabilities to participate in outdoor recreation alongside their peers. These experiences reduce stereotypes, raise awareness, and empower people to realize their full potential.

Website: [cgadventures.org](http://cgadventures.org)  
Phone: 435-713-0288 ■

## FACEBOOK

Want more contact with other people living with MS? The National MS Society is on Facebook . Facebook will also connect you to this chapter! Go to [facebook.com/nmssutah](https://facebook.com/nmssutah).

## FIT MS 2010 A STORY OF SUCCESS



**Alison Krutsch (right) with her daughter and Fit MS buddy Krista Krutsch. Winners of the Utah County Area Fit MS prizes.**

The National MS Society had another successful year for the Fit MS Wellness Challenge. Fit MS is a program designed to increase the health and well-being of all people with MS statewide.

Fit MS changed Utah County Area Winner Alison Krutsch's life, her health, and her outlook on her MS. Just over two years ago, Alison was told that she would have to be in wheelchair because of her weight and her MS. That was a low point for Alison. She had struggled with fatigue, depression and her weight over the years since being diagnosed with MS. She was unsure how to go about exercising safely. When she was told she would have to be in a wheelchair she decided that "something had to done!"

Alison looked online at the Utah State Chapter's website and found a new program called Fit MS was starting in January 2009. Fit MS aims to encourage participants to focus on one simple task a day in three areas: Mind, Body and Spirit. Participants focus on activities such as doing a puzzle, drinking water, eating enough fruits & vegetables or reading a book. These tasks performed on a daily basis slowly build healthy habits.

Alison indentified with the Fit MS program and felt she could focus on one small thing a day in all three areas and do what she felt like she could do. She realized that she "did not have to do everything" and she needed to "put aside time for me."

By participating in Fit MS Alison has lost over 120 pounds! She's also left the wheelchair behind. She credits the Fit MS program for helping her change how she thinks about doing hard things. Alison would tell anyone out there who is struggling with their MS, their health and weight that it is possible to make a change!

This year the Fit MS program allowed participants to compete with a buddy. Alison chose her daughter Krista Krutsch. They both say that competing together has brought them closer and helped them motivate each other to be healthy. Alison and Krista each won an iPod for being the buddy pair with the highest points in their area. ■

## FITMSWINNERS

### Overall Buddy Winners:

Abby West and buddy  
Karey Spransy  
Salt Lake City, UT

### Overall Individual Winner:

Bob Welker  
Salt Lake City, UT

### Southern Utah Area:

Marianne Hales Harding  
and buddy Michelle  
Dolinar  
St George, UT

### Salt Lake City Area:

Alan Babcock  
Salt Lake City, UT

### Northern Utah Area:

Donna Varnell and buddy  
Marianne Nelson  
Ogden, UT

### Utah County Area:

Alison Krutsch and buddy  
Krista Krutsch  
Springville, UT

### Central Utah Area:

Peggy Smith  
Joseph, UT

### Eastern Utah Area:

Danny Velasquez and  
buddy Tami Velasquez  
Price, UT

## SELF IMPROVEMENT GRANTS

Have you been thinking about getting healthy? Now is the chance to take steps toward a healthier lifestyle and the National MS Society is here to help you with a new program: Self Improvement Grants.

This program is designed to help fund and encourage overall wellness for people with MS.

The grant covers activities such as meeting with a nutritionist or personal trainer, taking a yoga or spin class, or physical therapy co-payments.

Self Improvement Grants will fund up to \$150/year per person and are on a first come first serve basis.

Apply today!

Download an application on our website at [cureMSUtah.org](http://cureMSUtah.org) or call 1-800-344-4867 option 1.

*Paid Advertisement - Not A National MS Society Program*



## Understanding & Treating RRMS

**Featured Speaker(s)**

**Chris Hammond, MD**

**Ogden Clinic Neurology**

**MS LifeLines Ambassadors Ted & Carlie**

**Friday, June 11<sup>th</sup>, 2010**

### **BOONDOCK'S FAMILY NIGHT**

**Picnic Pavilion 6PM**

**1525 Deseret Drive, Kaysville UT**

**(Exit 328 I-15)**

**BBQ Picnic/Limit 6**

**To Register: Call Toll free 1-877-329-8327**

## WHEN THE DIAGNOSIS IS PRIMARY PROGRESSIVE

Call 1-800-344-4867 for your free copy of Primary Progressive Multiple Sclerosis: What You Need to Know.

In this 156-page-book, experts Dr. Jack G. Burks, Dr. Nancy J. Holland and Dr. Diana M. Schneider address symptom management, treatment options, rehabilitation, technology and adaptations, quality-of-life issues, care-partner resources and much more.

The book, jointly sponsored by the Society and the Multiple Sclerosis Association of America, comes with a companion DVD, featuring five people

who are living with primary-progressive MS. Their comments also appear throughout the book, grounding the advice in real-life situations.

The book and DVD were developed following recommendations from a Society task force on the needs of people affected by this type of MS. Publication and free copies to people with primary-progressive MS have been made possible by a generous educational grant from Genentech.

For more facts and strategies, visit our online webcast series at: [nationalMSSociety.org/ppmsweb](http://nationalMSSociety.org/ppmsweb). ■

## IN MS, RELATIONSHIP MATTERS

WHEN YOU KNOW HOW TO TAKE CHARGE AS A COUPLE, MS DOESN'T HAVE TO RULE YOUR RELATIONSHIP.



A Relationship Matters class in action. Photo courtesy of Christian Brown

MS doesn't make relationships easier, but it can make them matter even more. The Society's amazing Relationship Matters program for couples living with MS has been making a powerful difference. As one participant put it, "After 22 years I thought we were pretty good (but) I learned a lot of new ideas."

Classes are offered in person, online and via teleconferences, so couples may choose the format that best suits their lifestyle and comfort zones. All offer interactive curricula on challenges related to MS.

Registration is ongoing. Just call 1-800-344-4867 or e-mail [couplesprogram@nmss.org](mailto:couplesprogram@nmss.org). ■

## CONSIDERING LIFE INSURANCE? A BROKER CAN HELP

BY KIM CALDER



It's nearly impossible to qualify for disability or long-term care insurance after being diagnosed with MS.

But life insurance is another matter.

### **Comparison shopping is a must.**

The premium for a person with MS will be higher, but the policies are out there. Shopping for the best, most affordable policy can be a time-consuming and complex challenge. A good insurance broker will not only do the research and educate a buyer about appropriate products, but will help with the application process and negotiations.

Licensed independent insurance brokers are professional advisors with expertise in the insurance marketplace. Some focus exclusively on one insurance company's products and act as sales agents, or "captive" brokers, negotiating, or "brokering," sales for that company alone. Others

develop expertise in specific types of policies, or "niche markets," for certain types of clients, such as retirees, newlyweds or even people with chronic diseases.

### **An "impaired risk" broker?**

An impaired risk specialist is particularly knowledgeable about what is available for people with health conditions or other risk factors. Some impaired risk brokers are even considered super-specialists, as they specialize in a few specific impairments, such as MS.

If you choose to work with a broker, select one with whom you feel comfortable and prepare to be very candid about your disease and circumstances. A good broker can help you determine if your expectations are realistic, your goals are clear and your timing is right.

Never hesitate to ask a broker for professional references, and check them out.

If someone refers you to one broker in particular, ask why. What did your referral source like about how this broker worked?

### **The bottom line.**

It is ultimately your responsibility to understand the terms of your insurance policy, and to make best use of it. Take advantage of the time when your broker is gathering your information and exploring your options to ask lots of questions.

It is not always possible to know what your final rate will be until you apply, but you do have the choice whether or not to accept or keep a life insurance policy during the "free look" period after it is issued.

Kim Calder is Director of Insurance Initiatives for the Society. ■

**TO REGISTER FOR ANY PROGRAM, CONTACT THE SOCIETY AT 800-344-4867, OPTION 1 OR VISIT CUREMSUTAH.ORG.**

## MAY

**Brain Health Education Series: Stroke Prevention and Awareness**  
May 21, Noon-1:00pm  
University of Utah Imaging and Neurosciences Center  
729 Arapeen Drive, Salt Lake City

**Brown Bag Lunch: MS and Exercise**  
May 21, Noon-1:00 pm  
Provo College  
1450 West 820 North , Provo

**MS Update: New Medications and More, Dr. John Rose**  
May 21, 4:30-5:30pm,  
Knight Education Center  
616 South 300 East, St. George

## JUNE

**Financial Planning and Education Series**  
**Topic: Employment**  
June 8, 6:30pm-7:30pm  
Old Mill II  
6340 South 3000 East, Suite 500  
Salt Lake City

**Financial Planning and Education Series.**  
**Topic: Insurance Needs**  
June 15, 6:30pm-7:30pm  
Old Mill II  
6340 South 3000 East, Suite 500  
Salt Lake City

**Brain Health Education Series: Financial Health for Seniors**  
June 18, Noon-1:00pm  
University of Utah Imaging and Neurosciences Center  
729 Arapeen Drive, Salt Lake City

**Financial Planning and Education Series**  
**Topic: Financial Management**  
June 22, 6:30pm-7:30pm  
Old Mill II  
6340 South 3000 East, Suite 500  
Salt Lake City

**Bike MS Harmons Best Dam Bike Ride**  
June 26-27  
Cache Valley Fairpark, Logan

**Financial Planning and Education Series**  
**Topic: Government Programs and Estate Planning**  
June 29, 6:30pm-7:30pm  
Old Mill II  
6340 South 3000 East, Suite 500  
Salt Lake City

## JULY

**Brown Bag Lunch: Organizing Your Life**  
July 8, Noon-1:00 pm,  
Utah Valley Specialty Hospital  
306 River Bend Lane, Provo

**Brain Health Education Series: Topic TBD**  
July 16, Noon-1:00pm  
University of Utah Imaging and Neurosciences Center  
729 Arapeen Drive, Salt Lake City

**MS 101**  
July 29, Noon-1:00pm  
University of Utah Imaging and Neurosciences Center  
729 Arapeen Drive, Salt Lake City

## AUGUST

**Multiple Sclerosis Research Symposium**  
August 7, 8:30am-12:30pm  
Radisson Hotel  
215 W South Temple  
Salt Lake City

**Multi-State Teleconference Series: Alternative Therapies**  
August 12, 7:30-8:30 PM

**Brain Health Education Series: Topic TBD**  
August 20, Noon-1:00pm  
University of Utah Imaging and Neurosciences Center  
729 Arapeen Drive, Salt Lake City

**Multi-State Teleconference Series: Depression and MS**  
August 26, 7:30-8:30 PM

## PEER SUPPORT A VOICE ON THE OTHER END



Facing the uncertain future of living with MS can be quite scary and isolating. Sometimes talking with someone who is experiencing or has experienced

the same challenges can make all the difference. Receiving support from a peer can be a great help by creating a unique supportive connection through a common bond. This program is open to anyone living with MS - from newly diagnosed to those living with the disease for many years.

The Utah State Chapter's Peer Support Program matches people to trained peer volunteers who also have MS. These trained volunteers are available to listen, answer questions, supply information, and provide support.

Through regular phone conversations, participants and

peers discuss such things as:

- employment concerns
- disclosing a diagnosis
- coping with fatigue, pain or other symptoms
- MS treatment options
- finding resources
- managing relationships with family and friends

**For more information or to enroll in the Peer Support Program, please contact the Chapter at 800-344-4867, option 1. ■**

## GET CONNECTED STAY CONNECTED

Staying connected with others is an important ingredient to a fulfilling life. The Society would like to help you do this by creating social groups for people living with MS across the state. Potential group themes might include a hiking group, movie nights, moms with MS, young adults with MS, and lunches for professionals with MS.

All successful groups need great leaders. If you are interested in starting a social group in your area for people with MS, contact Rachael at [rachael.lyon@nmss.org](mailto:rachael.lyon@nmss.org) or 800-344-4867, option 2. To express an interest in attending a group, or to suggest another group theme, visit our website at [cureMSUtah.org](http://cureMSUtah.org).

## SELF-HELP GROUP MEETINGS

The Utah State Chapter of the Society has several different self-help groups that can provide valuable information and support in a friendly environment. Self-help groups are made up of people who can share similar experiences in managing MS symptoms in everyday living. The groups are led by volunteers with MS who have received specific training from the Society.

Each group is unique and open to everyone - those with MS, spouses, family and friends. **To see a complete list of our state-wide groups please go to our website at [cureMSUtah.org](http://cureMSUtah.org).**

## FINANCIAL PLANNING FOR A LIFE WITH MS

### FINANCIAL EDUCATION PARTNERS ARE HERE TO HELP



The Society would like to introduce you to our Financial Education Partners (FEP) program which provides financial counseling and education free of charge to people living with MS. These services are offered through the Foundation for Financial Service Professionals. This exciting program will provide a series of classes with different topics relative to financial planning. It also matches professional financial planners with people living with MS to help address specific concerns. Examples of topics that financial planners may be able to address include:

- Basic budgeting
- Comparing pros and cons of

- different ways to save
- Understanding financial eligibility for need-based programs
- Understanding financial details of health insurance coverage and maximizing benefits
- Long-term care, retirement, and estate planning

Learn more about each of these topics by attending our Financial Planning and Education series (see page 11 for details).

For a free copy of "Adapting: Financial Planning for a Life with Multiple Sclerosis" or for any questions regarding this program, please contact the Society at 800-344-4867, option 1. ■

## PHARMACEUTICAL COMPANIES PROVIDE FINANCIAL ASSISTANCE FOR THOSE WHO QUALIFY

Many pharmaceutical companies have financial assistance programs to assist qualified individuals with the purchase of MS drug therapy. Benefits of these programs may include reduced or zero co-pays. Several of these programs are listed below.

Pharmaceutical Company: Bayer  
 Drug Therapy: Betaseron  
 Financial Assistance Program Name: BETAPLUS  
 Website: betaseron.com Phone: 800-788-1467

Pharmaceutical Company: Biogen Idec  
 Drug Therapy: Tysabri, Avonex  
 Financial Assistance Program Name: MS Active Source

Website: msactivesource.com  
 Phone: 800-456-2255

Pharmaceutical Company: EMD Serono  
 Drug Therapy: Rebif  
 Financial Assistance Program Name: MS Lifelines  
 Website: mslifelines.com  
 Phone: 877-447-3243

Pharmaceutical Company: Teva  
 Drug Therapy: Copaxone  
 Financial Assistance Program Name: Shared Solutions  
 Website: copaxone.com/supportservices  
 Phone: 800-887-8100

## ORAL DRUGS MAKE PROGRESS AMPYRA NOW AVAILABLE

Oral drugs for MS are getting even closer to the doctor's office, with one, Ampyra, now available by prescription.

The FDA approved Ampyra (dalfampridine, Acorda Therapeutics) in January for its ability to improve walking in people with MS. People with MS and their healthcare providers can call 888-881-1918 for information on Ampyra, including patient assistance programs and insurance coverage. (The drug is costly: wholesale price is estimated to be \$1,056 for a 30-day supply.) Watch Dr. Patricia Coyle talk about what Ampyra does, how it works and possible side effects at [nationalMSSociety.org/ampyra](http://nationalMSSociety.org/ampyra).

Gilenia (formerly called FTY720 or fingolimod) in an exciting development has been granted a priority review by the FDA. This means it could take as little as six months to determine if this will become the first oral disease-modifying drug for MS. Read the studies thus far at [nationalMSSociety.org/gilenia](http://nationalMSSociety.org/gilenia)

With positive results in the latest studies, Cladribine, another oral disease-modifying drug, is in the process of applying for marketing approval. Visit [nationalMSSociety.org/news](http://nationalMSSociety.org/news) and type "cladribine" in the search field to learn more. ■

## SOCIETYNEWS

Get the latest news on oral drugs sent directly to your inbox. Visit [nationalMSSociety.org/signup](http://nationalMSSociety.org/signup) to create a user profile and start getting the MS eNEWS!

## STAY INFORMED ON CCSVI DR. PAULO ZAMBONI MEETS WITH SOCIETY LEADERS



**Society leaders meet with CCSVI researcher Dr. Paulo Zamboni (second from left) at a NYU briefing chaired by Dr. Joseph Herbert (second from right).**

There's been a lot in the news lately about CCSVI, a blood flow drainage abnormality in the brain and spinal cord that some studies indicate may be linked to the damage wrought by MS.

The Society is pursuing this potential MS lead by undertaking the funding of new research in CCSVI (chronic cerebrospinal venous insufficiency) in MS and has invited investigators worldwide to apply for grants on the topic. We're collaborating with the MS Society of Canada to convene an international panel of experts to conduct an accelerated review of proposals and working with our sister MS Societies around the world to assure that our research strategies are coordinated. New CCSVI research projects are expected to begin July 1, 2010.

To stay up-to-date on the latest developments on CCSVI research, visit [nationalMSSociety.org/CCSVI](http://nationalMSSociety.org/CCSVI). ■

## MS ACTIVISTS MAKE MS A PRIORITY ON CAPITOL HILL SOCIETY VOLUNTEERS PUSH FOR INCREASED RESEARCH



At the 2010 MS Public Policy Conference, MS Utah Advocates **Darlene Morris, Earl Morris, Brook Osterland and Jenn Gonnely on Capitol Hill.**

activists pushed forward major initiatives that could lead to increased MS research, in turn greatly improving understanding of the disease itself.

### More knowledge needed

Currently, there are no accurate estimates of how many people in the United States have MS. A national MS registry could provide invaluable information on the incidence and prevalence of the disease, allowing researchers to investigate potential geographic, genetic or environmental risk factors.

Toward this important legislation, MS activists, who gathered in Washington, D.C., this March, sought co-sponsors for the **National MS and Parkinson's Disease Registries Act.**

### Supporting respite programs

The availability of respite care for all age and disability groups is at a dismal low. While the **Lifespan Respite Care Act** was passed in 2006, the program has been severely underfunded ever since its creation.

Activists urged legislators to commit a much-needed \$94.81 million to help stressed-out families and caregivers.

### Increasing research funding

For the more than 20,000 U.S. veterans diagnosed with MS, as well as all others living with the disease nationwide, more research funding from the Department of Defense could make a real difference.

Activists are requesting a \$15 million appropriation to the **DoD's Congressionally Directed Medical Research Programs** for MS research. Supportive legislators are already taking action, circulating a Dear Colleague letter in the House of Representatives and in the Senate. ■

## SOCIETYADVOCACY

To find out more about MS advocacy and how to get involved in public policy issues, visit [nationalMSsociety.org/advocacy](http://nationalMSsociety.org/advocacy). Or call our office to find out about state and local issues. 800-344-4867 option1.

## GIVING BIKE MS A SHOT

### MARIANNE RIDES BIKE MS WITH MS



**Marianne proudly sporting her Spokes Club jersey, getting ready to load up her electric bike for Bike MS.**

Marianne's MS began at the age of 27 when she unintentionally started walking into walls and experiencing other disconcerting physical symptoms. It wasn't long after that that her handwriting became totally illegible, she had vision problems and even worse trouble walking. As she began to manage her disease and regain control of her body, she decided to do something active to fight MS. She participated in Walk MS five years in a row.

It wasn't until her sister, Michelle, an avid biker and Bike MS team captain, wore her down with relentless encouragement that she chose to ride in 2008. "I'm not a cyclist or even all that athletic to begin with," Marianne explains. She worried that her MS would keep her from riding so much as a single mile. "When I read that electric bikes were permitted in the ride, I was intrigued." She called around and a local store, EcoMoto, agreed to loan her an electric bike for

the event. A poorly timed bout of the flu and her pregnancy kept her from being able to ride that year. But she wasn't done trying.

In 2009, Marianne got her chance. She rode an incredible 47 miles, using the motor just for the hills. "Even with that help, it was a struggle," she says. "I pushed pretty hard and was very proud that I made my goal." We were pretty proud, too. With memories of enjoyment and exhaustion, Marianne has already signed up for 2010. More than that, her sister has convinced her to sign up for a triathlon as well.

Marianne hopes that her story encourages others who don't consider themselves to be athletic to give Bike MS a shot.

In her first year at Bike MS Marianne raised \$625, earning a spot in the Bike MS Spokes Club. Gearing up for 2010 she has already raised over \$1,300 and shows no signs of slowing down. If you want to read more about Marianne's story, support her ride or gather some more inspiration to register yourself, visit her profile at <http://main.nationalmssociety.org/goto/marianne>. Thank you, Marianne, for sharing your story with us. ■



**Marianne showing off her Bike MS bib. Marianne rides for "A Cure in My Lifetime."**

## EVERYONE CAN JOIN WALK MS AND BIKE MS WE NEED YOUR HELP

Do you rely on the Utah State Chapter for programs, services or important research news and breakthroughs? Did you know these services are made possible because of Bike MS & Walk MS? They fund nearly 80% of the Utah State Chapter's operating budget. Help us exceed our goals by registering to join us today.

You've got a wedding the same day? You don't own a bike? Your MS makes it impossible to walk more than a block? You can still participate, even if you aren't there in person. People with MS across the nation have found a variety of ways to take part in Bike MS or Walk MS events.

To date, Walk MS Utah has raised \$350,000 statewide just short of our \$415,000 goal. If every one of the 30,000 Utahns affected by MS made a pledge to raise just \$15 we could EXCEED this goal.

"Virtual" riders and walkers often do everything a Bike MS or Walk MS participant does, without actually riding or walking. They may create a team, raise money and even earn fundraising prizes. They walk

in their own neighborhood on a day that works for them. They ride an exercise bike in their own home to log the same 150 miles as a Bike MS rider, but at their own pace. This year more than ever the Utah State Chapter needs your help to attain our fundraising goals and continue growing. If you have questions about what YOU can do TODAY, please call us at 800-344-4867, option 2. ■



2010 Walk MS Salt Lake City at The Gateway.

## LIVING IN A FACILITY IS NO BARRIER



For the last six years, residents at Quality Living, Inc., in Omaha, Neb., have conducted their own MS event, by walking around the QLI campus on routes suited to their level of ability. "Some routes are shorter than others and we provide assistance for those who need it," Campus Leader Mashanda Graham said. "No one feels left out."

Friends and family come out for this event, which includes a T-shirt design contest and breakfast with "the local pancake man."

"It's just a fun event," Graham said. But more than that, it keeps residents involved. "It's a way to support our residents with MS, and they enjoy it so much we keep doing it," she added.

## UTAH'S GENEROUS FAMILY FOUNDATIONS HELP KEEP YOU MOVING

If you look around the communities in which you live, you will often see buildings or projects named in honor of some of Utah's larger family foundations, such as the Eccles, Sorenson, Huntsman and other foundations. Through their generous support, they have improved communities throughout the state by making it possible to build the schools, hospitals, libraries and other facilities that many of us have access to.

These foundations also support the National MS Society by helping to fund our Financial Aid Program, our MS Wellness Program, and our MS Scholarship Program. They help us provide emergency funding to keep the utilities on in the winter or to provide air-conditioning in the summer; to make sure you can get to and from medical appointments; to help modify your home or car to ensure you still have access to your world. They help us provide Self Improvement Grants designed to keep you active and well, regardless of MS. They help us keep you moving by helping provide physical therapy, exercise classes, and home exercise videos.

And they help the high school senior who has MS, or who has a parent with MS, to be able to get started down the path towards getting a college education.

We would like to express our thanks to the many foundations who support the Society each year:

Ashton Family Foundation, Frances R. Burton Foundation, Castle Foundation, Lawrence T. & Janet T. Dee Foundation, Katherine W. and Ezekiel R. Dumke Jr. Foundation, Dr. Ezekiel R. & Edna Wattis Foundation, George S. and Dolores Doré Eccles Foundation, Henry W. & Leslie M. Charitable Foundation, the Val & Edith Green Foundation, Kennecott Utah Copper Charitable Foundation, Melba McKenzie Charitable Trust, Herbert I. & Elsa B. Michael Foundation, Ray & Tye Noorda Foundation, Rocky Mountain Power Foundation, Sorenson Legacy Foundation, Steiner Foundation, C. Scott & Dorothy E. Watkins Charitable Foundation, Wheeler Foundation, and the Vern & Marva Wolcott Charitable Foundation. ■

## SOCIETYGIVING

Find out more about foundation giving at [cureMSUtah.org](http://cureMSUtah.org) or by calling 800-344-4867 option 2.

## MEMORIALS AND TRIBUTES

### MEMORIALS

**Lisa Jan Conner-Bean Gentry**  
Amanda Chew-Stebbins

**Nancy Ruth Gehrig**  
Beverly & Gerald Randall

**Lisa Gentry**  
Shirley & Ron Morris

**Teree Lazzelle**  
Barbara Jacques  
Jackie & Frank Ovaitt

**Gordon Oettli**  
Linda Crane

**Tim Paine**  
June Heck  
Jennifer Jacobs  
Paula and Lloyd Johnson  
Rosalie McNamara  
Bessie and James Papastamos  
Jennifer Parsons-Soran

**Carol E. Roberts**  
Jane Getzelman

**Eugene Swerdloff**  
Rayna and Glen Mintz

### TRIBUTES

**Beth Whyman**  
Jennifer Bohannon

**Kenneth Bilger**  
Mark Olson

**Helen Huley**  
Saint John the Baptist Office Staff

*In lieu of gifts for special events or flowers for the loss of a loved-one, many choose to make a donation in honor or memory of someone special. If you would like to make a donation, please visit our website at [curemsutah.org](http://curemsutah.org) or call 800-344-4867 option 2.*

## VOLUNTEER SPOTLIGHT

### LAURA HAEFFELE SPECIAL EVENT LEADER



My dad was diagnosed with MS about 6 years ago and has been struggling with it ever since. You don't really know what MS is until you see it in someone that you love everyday. A few of my amazing

friends and I decided to get involved about four years ago when we realized in conversation that we were all linked to someone that was suffering with this illness. It was a no brainer for us, so we signed up for Walk MS and hoped for the best.

Participating in that Walk was just the beginning of my love for the Society. We started volunteering for all of the events that they put on throughout the year. Every event brings new faces, old faces, memories and that warm feeling when you know you're making a difference.

This whole experience has forever changed me and my outlook on life. I now choose to get up at four in the morning and get breakfast ready for the thousands of cyclists at Bike MS. I choose to spend hours

blowing up 1800 balloons so that our walkers can each have one at Walk MS. I choose to be a leader and encourage anyone I can to join us. I truly find fun and excitement in leading a team of volunteers to make the perfect event.

The staff members of the Utah State Chapter make it known how much they appreciate us and they couldn't do it without us. What they don't realize though, is that we appreciate them even more for the opportunity to be involved and thank them for making us who we are today.

Laura is one of 12 Special Event Leaders who are trained to manage and oversee key functions of the Society events. Learn about volunteer opportunities by contacting Seth Bowers at [seth.bowers@nmss.org](mailto:seth.bowers@nmss.org). ■

## MS DAY OF SERVICE

### HELP FAMILIES AFFECTED BY MS THIS FALL

The Chapter will hold our first MS Day of Service this September. Volunteer teams will work with families affected by MS to work on projects around their homes. Projects may include yard work, painting, home repairs or minor modifications, and general clean up. To apply as a volunteer or to nominate someone for the MS Service Day, please visit our website at [cureMSUtah.org](http://cureMSUtah.org) or call us at 800-344-4867, option 2.

## THE STAND TO CURE MS

### SAVE THE DATE

The Stand to Cure MS, a lemonade stand campaign to create awareness about MS and the Society, is set for August 20-21. This all-volunteer outreach program partners with Harmons, Associated Foods, A Fresh Market, Dan's, Dick's, Lin's and Maceys stores in communities from Logan to St. George and everywhere in between. Contact the Society at [cureMSUtah.org](http://cureMSUtah.org) or 800-344-4867, option 2 to volunteer.



National  
Multiple Sclerosis  
Society  
Utah State  
Chapter

6364 S. Highland Drive, Suite 101  
Salt Lake City, UT 84121

NON-PROFIT  
ORGANIZATION  
U.S. POSTAGE  
PAID  
Salt Lake City, UT  
Permit #2318

Change Service Requested

# One mission : MS remission

Our mission to stop a disease like multiple sclerosis requires not just a single-minded focus—but one that's as relentless as the disease itself. That's why at Biogen Idec and Elan, we view fighting MS as not only our job at work, but as our mission in life.



*Committed to a cure*