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# msconnection

Southern California Chapter

## New MS Treatment

**T**he FDA gave people with MS and their loved ones a new reason to be thankful this past holiday season. On November 23<sup>rd</sup>, the FDA approved natalizumab (Tysabri®, formerly known as Antegren) to reduce the frequency of clinical relapses in relapsing forms of MS, creating another treatment option for those with relapsing MS.

The approval was based on results from the first year of two ongoing clinical trials of the drug alone or in combination with Avonex®. Tysabri reduced the rate of clinical relapses by up to 66% and reduced the development of new or newly enlarging MRI-detected brain lesions. A greater proportion of those on therapy remained relapse-free. As part of this approval, the manufacturer has made a commitment to continue its trials of Tysabri for another year.

Unlike other drugs that have already been approved for treating MS, Tysabri is a monoclonal antibody that is given every four weeks by infusion into a vein. It is designed to interfere with movement of potentially damaging immune cells from the bloodstream, across the

*blood-brain barrier*, and into the brain and spinal cord. This approach was first explored in laboratory animal research, in part with funds provided by the National MS Society to Stanford investigators.

The drug appears to be safe and well tolerated; the most common side effects included headache, fatigue, urinary tract infection, depression, lower respiratory tract infection, joint pain, and abdominal discomfort. There is no information available about long-term safety.

Tysabri is administered in a doctor's office, clinic or hospital outpatient station. Infusions take about an hour. The cost per vial has been announced at \$1,808 (taken every 4 weeks, the yearly cost would be \$23,504). There is currently no information available about coverage see **New MS Treatment**, page 9



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HOPE

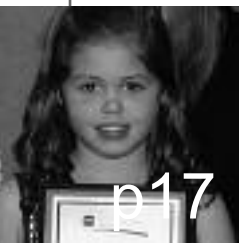


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nationalmssociety.



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Who will you walk for? Join the 2005 MSWalk. Details on page 12...

310.479.4456 and 1.800.344.4867

Publication of the  
National Multiple Sclerosis Society,  
Southern California Chapter  
2440 S. Sepulveda Blvd., Suite 115  
Los Angeles, CA 90064

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

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I was going to write about the important events at our National Conference this year, and so I emailed our National Board Member, Sue Meltzer, for her thoughts. Her response was so good, I asked her if I could use it all for my column this issue. Thanks Sue!

—Leon LeBuffe, Chapter President

**H**aving our National Conference in Denver this year was a perfect choice. We honored General **Mike Dugan**, our retiring CEO at Wings over the Rockies, surrounded by his familiar Air Force planes and a salute befitting a 4-Star General. His leadership these past 12 years has been incredible, with many accomplishments of which he can be proud. He will certainly be missed, and all of us hope to keep him involved at any level we can. He's too valuable to the National Multiple Sclerosis Society to let him walk away!

I was thrilled to be part of the selection team, as Chairman **Ed Kangas** announced our own *inside candidate*, Vice President of Field Operations **Joyce Nelson**, as the new CEO. Joyce is highly thought of among top national staff, local staff members who have worked with her and local presidents; this was clear from the great reception she received the moment her name was announced! She brings continuity to much that the Society has accomplished, she begins her new position at a very exciting time—the launching of Promise 2010 (see page 19), an intense research campaign—and she is already hard at work, planning for a great future. We look forward to her new ideas and directions.

And then, as if getting a new CEO wasn't enough, there was further

excitement in the announcement of **Weyman Johnson** as our Chairman-elect. Weyman will take over in a year from now and what a great choice. He's a thoughtful and insightful national board member, always looks for a win-win situation and is inclusive in his approach toward everyone. Weyman is an attorney in Atlanta. His firm Paul, Hastings, Janofsky & Walker LLP has graciously given its blessing to this appointment and he will be quite busy for the next few years with this new adventure. I know that he and Joyce will work well with each other when his term begins.

That said, it is going to be a tough act to follow Ed Kangas, the current chair of the Society. I don't know if I have ever had the opportunity to work with someone so bright, quick and *right on*. He *gets it!* Perfectly! And he has brought out the best in everyone to accomplish the goals of the Society. He never forgets we are there for one reason only—to end the devastating effects of multiple sclerosis.

Come to think of it, all four of the people I've mentioned personify this goal. We are very lucky! This year's National Conference theme was **Believe**, and I think everyone left believing in the cause and believing there will be a cure.



Sue Meltzer

—Sue Meltzer is a Chapter Trustee and member of the Society's National Board of Directors.

## “Help!”—It’s OK

*Lately I am experiencing more difficulty using my hands for various tasks. I always enjoy wrapping holiday gifts, but this year when I tried cutting the wrapping paper and using tape, I became increasingly frustrated in the midst of my struggle. While some days are better than others, I feel that asking people to assist me with small tasks like this upsets me greatly. How can I ask for help when I already feel I am asking so much of others in my life?*



**B**ecause of the unpredictable nature of MS, ability levels may fluctuate for individuals over the course of a lifetime. A range of emotions, such as anger, frustration and sadness may accompany the changes in physical ability. Though these feelings are typical, as one realizes new physical boundaries and limitations, he/she can discover creative ways of accomplishing intended goals.

Sometimes an individual can achieve targets alone in small, simple steps, but other times it may require asking someone for help. In the above example, someone else might assist in cutting the wrapping paper, but that still leaves the job of choosing the kind of paper, ribbon, bows, etc. and allowing the opportunity to apply some decorations to the outside of the box. Just because the task might not be completed “the way you used to do it,” does not mean that a new way might not

be satisfactory or even better. A solitary project of wrapping gifts could change to a new tradition of sharing a festive afternoon with a loved one to wrap gifts for other loved ones!

Asking for help is not an easy thing for many individuals who have always viewed themselves as independent and capable of anything. Although the level of independence may change, taking the responsibility to ask for assistance is an independent decision in itself. People with MS need to communicate with family and friends about past and present abilities, discuss what kinds of help they might need, and help others to understand that these needs may change over time. With a kind and gentle ask for help, those who care are usually more than willing to step up to the plate.

### RESOURCES:

*MS and Your Emotions*  
*Taming Stress in MS*  
*A Guide for Caregivers*

Participating in a support group, either individually or with family members or friends allows sharing with others who are in a similar situation.

For those who may have more involved caregiving needs, the Society can offer referrals to local agencies. The Chapter also offers short-term financial assistance for respite care to provide time-off for full-time family caregivers.

Please call 1.800.FIGHT.MS for more information, referrals or financial assistance.

## Striving for Personal Achievement

**R**esolutions can be made at any time of the year. Susan V. was 54, diagnosed with multiple sclerosis fifteen years ago, and looking to make a healthy change in her routine.

One day while volunteering at the Chapter office, Leon LeBuffe recommended that if Susan was interested in wellness, she should check out the Marilyn Hilton MS

### Achievement Center at UCLA.

Susan, who is ambulatory, was hesitant to follow up on this suggestion at first. She wasn't sure if seeing and interacting with others who had greater disability levels would upset her. But Susan did give the Center a chance and her fears never materialized, in part because she saw that people with MS of all ability levels attend the Center and take advantage of the varied activities. What she found was, as she says, "a real support group, from everybody...staff, other members."

Susan joined the Center's day program in April 2004 and got right to work on her goal to build a fitness routine. When Susan was first diagnosed with MS, she thought she'd never exercise or belong to a gym. She explains, "Before coming to the Center, my fitness program was null and void. The Center has made me more aware of exercise options, and now I do (fitness activities) more than ever, even pre-diagnosis." Now Susan not only exercises weekly at the Center with fitness instructor Lauren Coleman, but she also



Susan V.

joined a gym on her own and works out up to two additional days each week. She enthusiastically tells others about the benefits she experiences, "It is good for my heart, my overall health, plus I have less tension in my back. I am also doing yoga, stretching my body and moving more than I did before."

Susan continues her visits to the Marilyn Hilton MS Achievement Center at

UCLA, and still plans to continue work on her fitness goals so she can keep improving her flexibility, strength and gait. As she participates in different activities that the Center offers, she's also added new goals to her list, such as improving her memory and cognition.

Can Susan believe that she ever even hesitated about making this positive step through the Center's doors? No. "I feel like I'm doing something good for myself, taking time for myself,

something just for me—not for my kids, my husband—for me."

If you have been living with MS for some period of time and you are ready to take control and make personal changes, then the Center's day program is for you. Like Susan, you set your goals and the staff will customize activities that you can use throughout the week to maximize your ability to live well with MS.

Enrollment is ongoing in this one-day-a-week, 10:00 AM–3:00 PM, program. Please call Stephanie Fisher at the Center at 310.267.4071 to learn more about this unique, empowering program.

## Timmy's Journey

**H**aving trouble telling your children about multiple sclerosis and how it may affect your family's lives? The National MS Society is pleased to introduce a new resource to help families living with MS. "Timmy's Journey to Understanding MS" is a 15-minute animated cartoon about a little boy's adventure in learning about his dad's MS.



Captain Kip S'myelin takes Timmy on a guided tour inside his dad's body using a special spaceship. This educational and entertaining video was developed by the Allegheny District Chapter and produced and animated by students from the Art Institute of Pittsburgh.

Our Chapter's members contributed mightily, too. Many thanks to **David Lander** and his daughter **Natalie** for lending their voices to Kip and Timmy, and to **Marilyn Hilton MS Achievement Center** member **John Davis** for narrating the father's part. Thanks also to **Tom Sherak** and **Revolution Studios** for arranging the recording of voiceovers produced by **Gary Leva** at **The Cimarron Group**.



*John Davis*

To borrow a VHS or DVD copy of "Timmy's Journey" from the Chapter's library, please call 1.800.FIGHT.MS.

And don't forget about *Keep S'myelin* to continue your child's education about MS. *Keep S'myelin* is a colorful newsletter

filled with stories, interviews, games, and activities that highlight a variety of topics about multiple sclerosis.

For kids who love to play on the computer, issues are available in an interactive online version at <http://www.nationalmssociety.org/Keep%20S'myelin.asp>. Or call Julia Hakim at 1.800.FIGHT.MS to receive a free, quarterly print version in the mail. Seventeen issues are currently archived online and the latest newsletter focuses on teamwork.

### JUST FOR TEENS

Teens who have a parent with MS and teens who are living with MS don't require a cartoon or games to teach them about multiple sclerosis. However, if MS is a part of their life, teens do need fun and creative opportunities to connect with their peer community.

*Teen Inside MS* is an online quarterly newsletter where teens share their letters, stories, poetry, photos, and art. A new issue is available online at: <http://www.nationalmssociety.org/Teen%20InsideMS.asp> and features articles by two winners of the 2004 Scholarship Program, a new article in the *Kaley's Kolumn* series contributed by Chapter member **Kaley Zeitouni**, and details of the *My Life* photography contest just for teens.

## Society Names New President & CEO

**T**he National Board of the National MS Society selected **Joyce Nelson** as the new President and Chief Executive Officer effective when General Michael J. Dugan retired January 1, 2005.

Joyce began her career with the National MS Society 21 years ago as a Development Manager with the Northern California Chapter. Two years later, she was selected to be Executive Director in the Mid America Chapter. In 1991, she joined the Society's national staff as the National Director of Campaign Development, and later was promoted to Vice President of Chapter Programs. For the last five years Joyce has been Vice President of Field Operations, encompassing all responsibilities for the Society's fund raising and for its relations with chapters. During this time she was instrumental in managing significant organizational initiatives including the Organizational Effectiveness Task Force, the Research Challenge of Champions, the Promise: 2010 Campaign, the Corporate Star Program, national marketing for major gifts planning and determination of the Society's governance practices.

In Joyce's acceptance speech at the National Conference, she recognized

General Dugan for his strong leadership over the last 12+ years. Among his many accomplishments during his tenure, Gen. Dugan led the charge to make the Society a chapter-driven organization with high standards. He made sure that all of our top-rated research proposals received funding, endorsed targeted research efforts, and built a strong foundation for the Society to become recognized nationally and worldwide for its research, and program and service efforts.

Joyce concluded her speech by saying, "We will determine, together, our future.

Our destination is clear: the cure for MS. The route is open for discussion. Thank you again for your confidence and I will strive to be worthy, every day, of the trust you have placed in me to accelerate our efforts to end multiple sclerosis and its devastating effects."

The Southern California Chapter has had the privilege to work with General Mike Dugan and our Board and staff thank him for his dedication to our mission. Joyce Nelson knows the Society inside out and has also consulted closely with our Chapter over the last several years. We are thrilled to have such an experienced and knowledgeable leader as our new President and CEO.



*Joyce Nelson*

## Research Progress in 2004

**T**hanks to its generous contributors, the National MS Society (NMSS) was able to invest nearly \$35 million in 2004 into over 300 MS research projects, including the launch of 115 new studies. Significant advances have been made in MS research, more than 160 clinical trials are underway around the world, and still other experimental drugs are in the pipeline. Key highlights of the year include:

- The National MS Society launched a new initiative to speed research on nervous system repair and protection in MS. The Society has invited proposals from research teams to compete for 4 or 5 grants of up to \$5.5 million each to pave the way for clinical testing of therapies to restore function in people with MS.

- The FDA approved Tysabri® for relapsing forms of MS (see cover story).

- A Harvard-led study supported in part by the Society, involving 187,563 women enrolled in the Nurses' Health Study, suggested that those with higher intake of vitamin D (in multi-vitamin supplements) may have had a reduced risk of developing MS. Further research is necessary to clarify these findings.

- A paper published from the Society-supported Sonya Slifka Longitudinal MS Study, following over

2,000 individuals with MS over a long period of time, reported on the first-ever national study of aging and MS. Results pointed to challenges for older participants with MS, including the tendency to be more severely disabled,

more likely to need help with daily activities, and less likely to have used MS disease-modifying therapies. Despite their disability and care needs, many viewed their health status and quality of life positively. Over time, this study will allow

investigators to tease out factors in individuals' lives that may influence disease course and quality of life.

- Researchers from Australia, supported in part by the NMSS, found evidence in brain samples suggesting that the primary pathology in some people with MS

involves a killing-off of myelin-making cells with little or no evidence of immune attack. If confirmed, these findings raise intriguing questions about the MS disease process and how it begins, about how and when the immune attack becomes involved, and about the potential for different forms and different underlying brain damage categories for MS.

- Results from a study of the oral immune-modulating drug laquinimod indicated that in 209 persons with relapsing forms of MS, the





drug was well tolerated. Those on a higher dose had significantly fewer new active MS brain lesions during 24 weeks of testing. Larger studies to explore the drug's potential in MS are beginning now.

- The NMSS established four new Collaborative MS Research Centers to speed the search for the cause and cure of MS by teaming up investigators from diverse fields focusing on promising avenues of research. The four new Centers involve top scientists at Cleveland Clinic, Yale, Johns Hopkins and Mayo Clinic and each is focusing on the exciting area of nerve tissue repair.

- An international team of investigators from Australia and the U.S., partially funded by the NMSS, successfully reduced the severity and duration of MS-like disease in mice by vaccinating them with "Nogo," a protein normally found in the brain that is known to inhibit nerve regeneration. They determined that the vaccinations caused the mice's immune systems to produce their own antibodies that neutralized Nogo's inhibitory activity



in the nervous system.

- Avanir Pharmaceuticals announced positive results from a Phase III clinical trial evaluating the oral drug Neurodext™ for treating the symptom of "pseudobulbar affect," a condition involving uncontrollable laughing and/or crying affecting a small proportion of persons with MS and some other neurological disorders. The company intends to apply to the FDA for approval to market the drug for pseudobulbar affect.

- Acorda Therapeutics announced preliminary results of a phase II clinical trial of

Fampridine-SR, an oral, sustained-release formula of 4-aminopyridine, to treat MS symptoms. According to the company, the drug showed a trend toward improved walking speed and significantly improved leg muscle strength. Fampridine-SR blocks tiny pores on the surface of nerve fibers, to improve nerve impulse conduction. The first studies of this ion channel-blocking approach in people with MS were supported by the NMSS.

### **New MS Treatment**, from page 1

by health plans.

There is also no information immediately available about the relative benefits or safety of Tysabri in comparison with any other available treatments for MS. People with MS who are interested in Tysabri should discuss their individual

situation thoroughly with their neurologist. The manufacturers, Biogen Idec and Elan Corporation, have established a toll-free number 800.456.2255 and Web site [www.tysabri.com](http://www.tysabri.com) for further information.

## BAND of HOPE

**Y**ou can help raise MS awareness—just wear the MS Band of Hope, a new nationwide awareness tool. Get a set of the red wristbands and distribute them to your family, friends or neighbors. Order a set for everyone in your department at work or even the whole office. If you are an MS Walk Team Captain, consider getting a wristband for each of your teammates. The more the public sees the MS Bands of Hope, the more they'll realize how many people the disease touches.

You may get a pack of a dozen wristbands for \$12 or in multiples of 25 for \$25 per pack. Call 1.800.FIGHT.MS or 310.479.4456, visit [www.ms-events.com](http://www.ms-events.com) or send the order form below to place your order today.



Mail to: **Band of Hope, National MS Society,  
2440 S. Sepulveda Blvd., #115  
Los Angeles, CA 90064**

**or Fax to:  
310.479.4436**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_

12 wristbands at \$12 + \$3.00 shipping

# \_\_\_\_\_ packs of 25 at \$25/each + \$3.00 shipping (FREE shipping for orders over 4 packs)

Total enclosed: \$ \_\_\_\_\_  Check or  Charge my:

Visa  MasterCard  AmExp  Discover



Card #: \_\_\_\_\_ Exp. Date: \_\_\_\_\_ / \_\_\_\_\_

Name on Card: \_\_\_\_\_

Signature: \_\_\_\_\_

## Westfield BANDS Together with NMSS

**A**cross the country Westfield Shoppingtowns are helping to increase awareness about MS, the National MS Society and the MS Walk. During an exciting promotion period between January 15–March 31, 2005, shoppers who visit a Westfield Shoppingtown will have the chance to make a donation to receive an MS Band of Hope and to place an MS Ribbon of Hope cutout in honor of a loved one on a Wall of Hope.

Shoppers may get the MS Band of Hope for a \$1 donation at local Westfield Shoppingtowns in Century City, Eagle Rock, Sherman Oaks, Culver City, Palm Desert, Woodland Hills, Arcadia,

Canoga Park and West Covina. These Shoppingtowns will also host MS Walk rallies and provide information about MS, research and our local Chapter programs and services.

Many thanks to Chapter Trustee **Arthur Schramm, Jr., Esq.** for his invaluable work to arrange this partnership between the Society and Westfield. "The new

Westfield and Society partnership is a tremendous opportunity to introduce millions of shoppers to the importance of the MS cause and build a long-term relationship with one of the nation's most prominent retailers," said Society President Joyce Nelson.

**Westfield**<sup>®</sup>  
SHOPPINGTOWN



*Arthur Schramm,  
Jr., Esq.*

## Welcome New Trustees

**T**he Chapter welcomes three new members to the Board of Trustees. **John Hall**, a senior banker with **Wells Fargo**, recently moved to Los Angeles from Denver where he was a longtime member of the Colorado Chapter Board. He was the Colorado Chair for three years and is also a former member of the National Board. **Sheri Safan** is another longtime volunteer. For years she has raised substantial amounts of money through her Recipes for Research dinner and has been a

volunteer fund-raiser for the Chapter and for UCLA in a number of other ways. **Randy Grossblatt** is Senior Vice President and Manager of the UBS Financial Services office in Beverly Hills. Randy has been a terrific fund-raiser for us the last two years and is very dedicated to the cause since he has a relative living with MS.

We look forward to working more closely with John, Sheri and Randy as they take on a leadership role with our Chapter.

## Walkers, We Need You!

**T**hank you to all of our 2004 MS Walk sponsors and participants who helped us raise a record \$1.2 million. Your contributions helped fund both cutting-edge research, leading to breakthroughs like Tysabri, plus meaningful programs for people with MS and their families, including new Women's Day and CogniFit programs. As we continue to expand our programming and as we launch the Promise 2010 research initiative, we again call on your generosity. Help us reach \$1.5 million in 2005!

Join the MS Walk 2005 at one of seven wonderful locations throughout the Chapter area on April 9th and 17th. Entertainment, great food, and lots of fun await you.

The MS Walk routes range from a 5K (3.1 miles) to a 10K (6.2 miles), with a special 1K available so everyone can participate. Each site's route is accessible and help is available along the route for those who might need extra support. Registration for all sites begins at 7:00 am with a warm-up and opening ceremonies at 8:30 am. The official MS Walk will start at 9:00 am. Lunch and festivities will start as soon as you cross the finish line.

### **Saturday April 9, 2005**

Choose from five locations on Saturday April 9, 2005.

**Bakersfield** treats the walkers to a stroll along the scenic Kern River Parkway Bike Path at Yokuts Park. Live musical entertainment greets the participants as they return.

Check out our newest location in **Big Bear**, where the bears won't scare you but

the mountain fresh air and the beautiful views will take your breath away. The route, along the Alpine Pedal Path, takes you around the edge of the lake and through luscious forests.

Don't miss the high desert in bloom. In **Lancaster** you will start at the Lancaster Marketplace and continue through blossoming areas of the city.

Get ready for the 'movie colony' in downtown **Palm Springs**. Walk in the location where stars of the past and present have lived and played. Take the last steps of the MS Walk around the tree-lined Ruth Hardy Park, one of the oldest parks in the Palms Springs area and the largest park in the downtown area.

MS Walk participants in **Redlands** will take a scenic and historic tour starting at the turn-of-the century Smiley Library.

### **Sunday April 17, 2005**

In **Upland** walkers will enjoy the beauty of the snow-capped mountains while staying warm in Upland Town Square. This site showcases the Upland community spirit at every turn (look for the homemade cookies at the first rest stop).

Be prepared for history and excitement at the **Greater Los Angeles** site where you will wind your way around the LA Memorial Coliseum, Rose Gardens, California Science Center, Natural History Museum, and through the beautiful campus of the USC Trojans

Visit [www.msevents.com](http://www.msevents.com) or call 1-800-FIGHT MS today to register for an MS Walk near you.

## Team Up!

**S**ure, you can participate in the MS Walk on your own. But think of how much more fun you will have if your family, friends, neighbors or co-workers walk with you. Teammates even make fund raising more exciting—you can challenge each other to see who will raise the most money or receive the highest pledge.

Forming a corporate team for the MS Walk is a powerful way for a company to demonstrate its involvement in the community. Participation in the event will also build camaraderie within the workplace. **Northrop Grumman** has participated in the MS Walk for many years and can't wait for this year's event.

Northrop Grumman is not alone. The **United States Postal Service** has their own team as well as **21<sup>st</sup> Century Insurance** and **Wells Fargo**. **Studley**, with their first year out, had 57 people and was also a corporate sponsor. **Marsh Inc.** gets their

company involved by posting the MS Walk information on their intranet for the entire company to read. They host breakfasts and also have fund-raising competitions between departments. The list of companies goes on.

Not enough quality time with your friends and family? **Team Engelman** solves this by walking together at the MS Walk. Team Captain Traci Engelman organized her 2004 MS Walk team from across the country. In their first year they raised over \$28,000 with 61 team members. She contacted new members and kept her team motivated, all through

email. When asked if she would do it all again, the answer was an overwhelming "yes, I will see you in 2005!"

Babs Pasternack first walked in the MS Walk with her mother over 15 years ago. Each year more of Babs' family and friends came out to join her. **Team Babs** now has 16 members who walk alongside her while she completes the route in her electric scooter. Even though Babs can't "walk" the route anymore, she makes sure she is there every year. "I do this not only because I



*Babs Pasternack*

want to support the important and crucial work of the National MS Society, but because the experience is a blast. I wouldn't miss it!"

No connection to multiple sclerosis? Not an excuse! People walk in the MS Walk for a variety

of reasons. One walker shared, "I started out walking because I wanted to help people in my community, but I return every year because of the friends I have made and the excitement of the event."

The MS Walk 2004 had over 550 teams ranging in size from 4 to 254 members. How big can your team be?

You can be an MS Walk team in 5 minutes. Team captains can register online at [www.msevents.com](http://www.msevents.com) and create a team Web page that can be used to communicate to teammates. Or call 1-800-FIGHT MS to register today.



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## Take the Challenge

**W**ith the huge success that the MS Challenge Walk experienced in 2004 in raising over \$1.1 million, it is no surprise that this year will be even more spectacular. Join hundreds of walkers as they journey three days and 50 miles closer to a cure. The MS Challenge

Walk has a spectacular route along the pristine shoreline from Carlsbad to San Diego. Hotel accommodations are provided for the weekend as well as stellar route support and fantastic food for your three-day adventure.

MS Challenge Walkers share a passionate commitment to find a cure to this devastating disease. Have you walked 50 miles in three days? You can do it! Make a difference and join the MS Challenge Walk today at [www.msevents.com](http://www.msevents.com) or 1-800-FIGHT MS. Join us for the experience of a lifetime!



**Register today for the MS Challenge Walk on September 14–16, 2005**



## Ralphs Rebates

**R**alphs Grocery Company wants to help its communities grow and prosper. Through their Community Contribution Program, you can register your Ralphs Club Card with the National MS Society. Every time you shop for groceries and use your Ralphs Club Card at checkout, Ralphs will make a donation to our Chapter, equal to 4%



of your monthly purchases.

Enroll today! E-mail your name, phone number, address and card number, found on the back of your Ralphs Club Card, to [msevents@cal.nmss.org](mailto:msevents@cal.nmss.org) or call Kelly McKnight at 1-800-FIGHT MS. Then, stock up on your groceries at Ralphs. It's that simple to make a donation in the fight against MS.

## Golfing With A Goal

**S**ure, golfers always want to score their personal best each time they step out on the course. But the 115 golfers who played in the **11th Annual MS Golf Classic** on October 11, 2004 also wanted to drive out MS. Participants certainly did their part by raising over \$70,000.

Foursomes played 18 holes at the Robinson Ranch Golf Club in Santa Clarita. Players took part in various contests and vied for one of four hole-in-one car chances sponsored by **Lexus of Valencia**.

Participants also competed off the course to be the highest bidders during the silent auction—from restaurant gift certificates to sports memorabilia, from artwork to vacation packages. Local restaurants and businesses donated over 100 items for the raffle and auctions. Auctioneer **Fran Dressler** drew excitement during a live auction after dinner, which included a

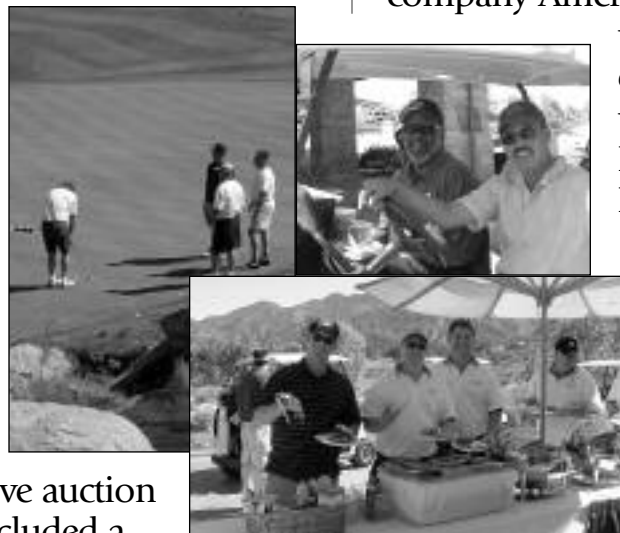
suite for a Lakers game and an opportunity to play in the Lexus Champions for Charity golf tournament.

In addition to all the fun, golfers and their families learned how the money they raise directly impacts the fight against MS. **Dr. John Mazziotta**, Chair of the UCLA Department of Neurology and Director of Brain Mapping Center, spoke about cutting-edge research happening right here in Southern California.

Many thanks to Honorary Chair, Olympic Gold Medallist **Rafer Johnson** and to special guests, actors **Jamal & Jerod Mixon**. A big thank you to Golf Committee Chair **Fred Arnold**, his company American Family Funding, and

to the entire event committee. Thank you also to sponsors **Mojave Pepsi Distributing, Anheuser-Busch Sales Antelope Valley and Charmaine's Florist**.

Save the date for the next MS Golf Classic on October 10, 2005.



## Volunteer Standouts

On November 7, the Chapter proudly honored the year's most exceptional volunteers.



**Sue Meltzer** received one of the Society's most prestigious awards, the *Norm Cohn Hope Award* for her 3 decades of outstanding volunteer efforts and leadership.

*Sue Meltzer* She has stepped forward as a member of the Chapter and National Boards, as a board member of The Marilyn Hilton MS Achievement Center at UCLA, and as the Chair of the Golden Circle campaign during a key period when the campaign quadrupled in annual income.



*Carolyn Roberts & Madeleine Sherak*

Madeleine Sherak, PhD presented the *Programs Key Award* to **Carolyn Roberts, PhD** for lending her professional expertise as a licensed marriage family therapist in counseling others with MS. This year she also developed and piloted an exciting new spirituality program to promote wellness.

The *Rookie Of The Year* award went to **Traci Engelman**. When Traci's brother was diagnosed with MS, she wanted to do something to help. She started MS Walk Team Engelman, and in her first year as a team captain, Traci organized over 60 team members and they raised \$28,225.



*Team Engelman*

**Susan Keith** accepted the *Grisanti Trustee of the Year Award* honoring her reign as the MS Walk champion for the last four years, raising more than \$160,000. Susan always attributes her success in part to the support of her strong partner, trustee **Jeanne Perry**, who presented the award.



*Susan Keith & Jeanne Perry*

**Julie Kaufer** received the *Development Key Award* for her work as co-chair of The Golden Circle. Julie has been instrumental in cultivating donors and her business savvy has helped the Chapter to grow the campaign in many new directions.



*Julie Kaufer and Sue Meltzer*

Trustee **Harland Green** presented the *Self Help Group Leader Award* to **Denise Kish** for the dedication she shows as she facilitates support groups in



*Denise Kish & Harland Green*

both the San Diego and Upland areas.



This year, we couldn't pick just one *Youth Volunteer of the Year*, and so we decided to honor 3 remarkable girls who have clearly demonstrated that age does not matter when it comes to making a difference. In her first year as an

MS Walk participant, seven-year-old **Bailee Flaughter** raised over \$4,000 in honor of her grandfather. **Cody**

**Knue** started the Fighters of MS team when she was only nine and since that time her team has raised more than \$6,000. Every week during the past three

summers, **Kelsey Linford**, with the help of her friends **Nadja and Anna Kennedy**, has been selling snow cones in the front yard. The girls went door-to-door with flyers, helping to not only drive business, but also to raise awareness about MS and the National MS Society.



*Kelsey Linford, Nadja & Anna Kennedy, Bailee Flaughter, trustee Julie Kaufer and Cody Knue*



*Lucky and Tony Van Beers with Jonathan Strum (center)*

**Lucky and Tony Van Beers** accepted the *Special Event Key Award* from Jonathan Strum for their work as volunteer leaders at the MS Walk. Playing host to over 5,000 walkers, they make sure all of the vendors, sponsors and volunteers work together to get the site ready for the tired walkers and then take care of them when they return.

Tom Sherak presented two *Public Awareness Awards*. Doreen Roberts accepted the award on behalf of **Viacom** for their generous annual donation of bus shelter and billboard space to promote the MS Walk over the past eight MS Walk seasons.

General Manager Vicki Connor-Medina also accepted an award on behalf of **High Desert Broadcasting** for raising a tremendous amount of awareness in the Antelope and Santa Clarita Valleys by promoting the MS Walk site in Lancaster on their radio stations over the last 3 years.



*Doreen Roberts and Tom Sherak*



*Vicki Connor-Medina and Tom Sherak*

We'd also like to recognize the awardees who were unable to attend the luncheon. Congratulations and thanks to trustee **Bruce Hecker**, of Bruce's Gourmet Catering, our *Volunteer of the Year*, for his continued generosity donating his gourmet catering services to many of our events including Golden Circle recognition events, the MS Challenge Walk and QVC's Cure by the Shore. Congrats also to **Sue Upshaw**, our *Peer Counselor of the Year* and to **Farmer John**, our *Volunteer Group of the Year*.

## The 2004 Golden Circle

*Thanks to the generosity of the following donors, The Golden Circle raised over \$680,000.*

### **Angel (\$50,000 +):**

Tuffli Family Foundation

### **Benefactor (\$25,000 TO \$49,999):**

Anonymous • COKeM International Ltd. • Shirley K. and Bruce I. Harris • UBS America

### **Patron (\$10,000 TO \$24,999):**

Gertrude Bennett • Elaine and Jack Bock, Jr. • Helen Bolsky • Melanie Grisanti and Gordon McLeod • Fred N. Hellmann • Lisa and Ray Karpe • Marca and Alvin S. Kaufer • Caroline and Stephen L. Kaufer • Michael J. Lichner • Jacqueline and Paul Mahoney • Fela and David Shapell • Edward H. Taran • Frederick R. Weisman Philanthropic Foundation

### **Sponsor (\$5,000 TO \$9,999):**

Donna M. and Dr. Walter F. Bauer • Wendy and Joel I. Bennett • Louis L. Borick, Louis L. Borick Foundation • Curt A. Bower, Parsons • The Corgel Family • Julie and John D. Curtiss • Frankie A. and John A. Duran • David Fogg, Tempurpedic, Inc. • Donna Garber • Jeff Glassman, Wallis Foundation • Debbie Goldman and Bob Harper • Kathleen Henninger • Charlotte B. and Dr. S. Lawrence Jacobs • Tatiana and Todd S. James • Jaquish and Kenninger Foundation • Kathleen Lange, Because You Can • Gloria Meeker • Arnold Seidel, Virginia Friedhofer Charitable Trust • Nathan Shapell, Shapell Industries, Inc. • Madeleine and Tom Sherak • Louise Laraway Teal Foundation • Dina Tecimer and Masood Sohaili • Linda and Dennis H. Vaughn • Florence M. Victor • Diana and Chester A. Widom • Lori Wilson • Martha B. and Charles C. Wolf

### **Friend (\$2,500 TO \$4,999):**

Anonymous • Aaroe Associates Charitable Foundation • LaVilla S. and Dean H. Adamson, Wilbur C. Grosse Trust • Rhona Bader • Camilla J. and Arnold W. Bramlett • Pearl Anne and Melvin Brooks • Kimberly Clary and David Morena • Mark H. Cridland • Joan E. and Dr. Floyd A. Davis • Linda Ellman and Gary Mandinach • Phyllis and Bill Gibson • Judy and Roy S. Glickman • Mary Ann Good • Ann R. and David E. Gooding • Vera and Paul Guerin • Charlotte Hughes and Christopher Combs • Patricia and Jonathan Jacobs • Marcy and James M. Kalina • Julie Kaufer • Susan W. Kozberg, Wolf Family Foundation • Sieny and Dr. Alex Krammer • Julena Lind and Leon LeBuffe • Iris B. Mahoney • Frieda Meltzer, Sue and Edward Meltzer • Senn V. Moses • Eugenia Riordan Mulé • Faith Pearlman, Jerome and Faith Pearlman Foundation • C. N. Franklin Reddick, III • Alison and Larry A. Rosenthal • Donald R. Rudkin • Eugene Safan • Sheri and Steven Safan • Dorothy and Charles B. Samuel • Sandra J. and Vincent E. Scully • Mace Siegel • Stella M. and James N. Smith • Ruth Lynn and Henry D. Sobel • Sidney Stern Memorial Trust • Jane and Lester E. Trachman • James S. Tyre • Susan and Philip T. Winik

### **Member (\$1,000 TO \$2,499):**

Anonymous (3) • Kathleen C. Anderson • Betsy and Harold Applebaum • Shirley A. Barkley • Claudia Barski and Peter J. Carian • John W. Bartlett • Joanne K. Beckwith • Ethel and Tom Beiseker • Hilda and Dan Bergher • Frieda and Alan E. Berlin • Barbara and Leonard Bernstein • Esther and Daniel Birnbaum • Kay and J. Alan Bloore • Vicki and Robert Bond • Barbara and Morton Bowman • June Boyer and Theodore Mandinach • Patricia A. and Franklin J. Brenner • Simon Bresler, Nancy and Sandy Bresler Fund • Leonard J. Brutocao, Brutoco Engineering • Debbie and James Burrows • Alban Calzada • Alexandra Carian • Judith A. Carroll • Stephen C. Carroll • Mr. and Mrs. Aaron C. Clark • Raymond M. Cohen • Geraldine P. Coombs • Sheryl and Glenn Cooper • Toni and Bruce Corwin • Dhunmai and Phirouz Dalal, Nadju and Farokh Dastur • Diana R. Davidow • Shirley Lu and Norman Davidson • Anita L. DeFrantz • Janet C. Dirks • Kerry A. Dolan • Barbara J. Eliades and Scott H. Dunham • Julie and Barry Engelman • Anna and Paul Feinstein • Sandra and Bernard Fischbach • Gloria and Stanley Fishfader • Pat and Robert Fleming, Paveco Construction • Brian D. Fox, B.D. Fox and Friends, Inc. • Edith and Arthur Furst • Margaret L. Gage • Sharlene and Sol F. Galper • Gibson, Dunn and Crutcher, LLP • Elvie and Yale Gieszl • Cynthia Gisser and Michael Torres • Richard A. Gleitman • Danny Goldman, Danny Goldman Casting • Elaine and Bram Goldsmith • Judy and David M. Goldstein • Edith M. Grady • Susan Ann and Ronald G. Graves • Karen L. Green • Sherri and Gary Haber • Donald Handelman, Meyer Handelman Fund • Steven N. Harwood • Alice A. and David M. Herald • Jan Herzfeld • Rosalind Hewsenian • Cynthia and Charles Hirschhorn • Johnny Holiday and John A. Taube • Linda G. and Roger H. Howard • Susan M. Howard • Gabriel J. Iglesias • Elaine Smith Irell • Charlotte J. and MacDonald H. Jones • Celia Kahn • Charlotte and Stanley Kandel • Karen Garver Karl and Donald E. Karl • Heidi Katz • Roberta and Bart D. Kaufman • Nicole G. and Bill Keck • Mr. and Mrs. Stephen Keefer • Tracy and Michael Kerkorian • Jacob Krueger • Elizabeth and Bradley La Cour • Maria and Howard Lapides • Dorothy and Edward Lazor • Frances F. and Jerry G. Leigh • Leon Lowenstein Foundation • Ann and Don Levin, Lenore S. Levin

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*The Golden Circle Committee also wishes to acknowledge all the donors who contributed to The Golden Circle 2004 Campaign with gifts up to \$999—Thank you!*

### *The 2004 Golden Circle Committee*

Julie Kaufer and Sue Meltzer, Co-Chairs

Rhona Bader	Paul Mahoney
Helen Bolsky	Pam Miller
Derrick R.E. Doba	Fern Seizer
David E. Gooding	Dina Tecimer
Michael Lichner	

## COMMIT TO THE CURE

In an effort to halt progression of MS symptoms and reverse the damage to the nervous system caused by MS, the Society is spurring the study of tissue repair and nerve protection by offering four to five grants of up to \$5.5 million each to fund collaborative group research. These are the largest grants ever offered by any funding agency for nerve repair research.

A worldwide “request for proposals” for this topic has been circulated, and many institutions have indicated their interest. After a thorough peer-review process, the Society will launch the partnerships in June 2005. Scientists and clinicians have a challenge to make tissue repair and protection a reality. Our challenge is to ensure they get funding to succeed.



The logo for 'Promise:2010' features the word 'Promise' in a large, elegant, cursive script font, followed by '2010' in a smaller, clean, sans-serif font. A small star is positioned above the 'i' in 'Promise'.

Sue & Ed Meltzer have made the lead gift for our Chapter to this innovative and important neuro-repair initiative.

Please consider following the Meltzers' lead and make a gift to Promise 2010. For more information about neuro-repair, Promise 2010 or other gifts to The Golden Circle, please call Kate McIntosh at 310.479.4456 x124.

## Let Us Write You A Check!

**D**id you know that in exchange for a gift of stock or any other appreciated asset, we can offer you an opportunity to set up a Charitable Gift Annuity with the National Multiple Sclerosis Society?

**Benefits:**

- An immediate tax deduction
- Guaranteed income for life
- Savings on Capital Gain taxes
- Membership in Pillars of Society

**Requirements:**

- Minimum must be \$10,000
- Donor must be 50 years of age when annuity payments begin (payments can be deferred)

**Sample Rates:**

**ONE LIFE**

Age	Rate
50	5.3%
60	5.7%
70	6.5%
80	8.0%
90	11.3%

**TWO LIVES**

Age	Rate
50 and 50+	4.7%
60 and 65	5.5%
70 and 75	6.1%
80 and 85	7.3%
85 and 90	8.4%

Please feel free to call me at 310.479.4456, ext. 109 for more information or to set up a confidential meeting to assist you with your gift planning.



*A. David Scholder,  
Senior Director for Estate  
and Gift Planning*

### **Workplace Giving is an easy way to support the fight against MS.**

Each year, over 1.5 million public and private sector employees designate their charitable contributions to nonprofit organizations nationwide through workplace giving campaigns.

You can help, too. To find out more about our Chapter's workplace giving efforts and to learn how you and your company can participate, contact Sheryl Miller at [sheryl.miller@cal.nmss.org](mailto:sheryl.miller@cal.nmss.org) or 310.479.4456.

## MS Advocate Appointed to State Stem Cell Panel

**O**n November 2<sup>nd</sup>, California voters approved Proposition 71, the California Stem Cell Research and Cures Initiative. This innovative and ambitious legislation created an Institute for Regenerative Medicine, which will manage \$3 billion in grants and loans for embryonic stem cell research at California hospitals, medical schools and universities.

A 29-member Independent Citizen’s Oversight Committee (ICOC) comprised of university chancellors and research and advocacy leaders has been selected to oversee the Institute. The California chapters of the National MS Society nominated our trustee **Dr. Jeanne Perry** from UCLA and Northern California Chapter volunteer **David Serrano-Sewell** to represent the interests of people touched by multiple sclerosis.



*David Serrano-Sewell*

On December 13<sup>th</sup>, Lieutenant

On January 10<sup>th</sup> Governor Arnold Schwarzenegger announced a MediCal redesign program as part of the new state budget. As we go to print on this issue of the newsletter, we do not yet have all of the details on how this will affect MediCal recipients who have MS. Please stay tuned...we will provide information soon online at [www.nationalmssociety.org/cal](http://www.nationalmssociety.org/cal) and in future issues of our newsletters.

Governor Cruz Bustamante announced the appointment of San Francisco Deputy City Attorney David Serrano-Sewell to the ICOC. David was diagnosed with multiple sclerosis over two years ago. Northern California Chapter President Julie Thomas explains, “Since his diagnosis David has committed himself, with fervor, to advocating on behalf of those individuals with MS and other chronic neurological diseases through the California NeuroAlliance, and serves as an articulate and effective voice for them.”

We are fortunate that such a skilled and dedicated advocate like David will represent the National MS Society and the voice of people affected by MS on this landmark ICOC. We hope this research initiative will lead to new treatments and cures for a multitude of diseases.

**Jeanne Perry, PhD**, Director of the Protein Expression Technology Center and Associate Adjunct Professor at UCLA, has accepted the position of our Chapter’s Research Advocate. In this role, Jeanne will



*Jeanne Perry, Ph.D.*

help the Chapter Board, the Chapter’s constituents, and the public to better understand the Society’s research program and research expenditures. Jeanne will also act as a liaison between the Chapter and David Serrano-Sewell and the ICOC.

## Gift Giving Made Easy

**G**iving a gift in honor of a loved one has never been so easy! No more tying strings around your finger or sending belated cards; now we will do the remembering for you! Celebrate a special occasion, honor a loved one or express your sympathy with a thoughtful tribute card. Your contribution will help the National MS Society support MS research and local services for people with MS and their families.

Now you can plan ahead and take care of shopping for all of your birthday, anniversary, and thank you gifts at the same time. Just tell us whom your gift will be honoring, where to send the card, and when you would like us to mail it out—we'll take care of the rest.

Please use the Tribute form on the next



## Generous Grantmakers

**T**hanks to the J.B. and Emily Van Nuys Charities for the recent grant of \$8,455. This award will support a portion of the Chapter's capacity-building technology upgrade project through the purchase of new laptop computers for staff.

We also greatly appreciate the support



page to make a gift in the name of someone you would like to honor.

Just complete the form and mail to 2440 S. Sepulveda Blvd., Suite 115, Los Angeles, CA 90064 or fax the forms to 310.479.4436. (Please feel free to make copies of this form if you would like to make additional gifts.) You can also make Tribute & Memorial gifts online at [www.nationalmssociety.org/cal](http://www.nationalmssociety.org/cal).

Please Note: You can now find the listing of recent Tribute and Memorial gifts by visiting our website at [www.nationalmssociety.org/cal/donation](http://www.nationalmssociety.org/cal/donation) and clicking on the Tributes and Memorials link. Or call Elicia Lopez at 310.479.4456 ext. 111 or 1.800.FIGHT.MS if you have any questions or to request a copy.

of Supervisor Zev Yaroslavsky, Third District of Los Angeles County, for the recent \$6,000 grant. These funds will support renovations to create an additional accessible restroom at The Marilyn Hilton MS Achievement Center at UCLA.

**GIVER — Your information**

First Name: \_\_\_\_\_ MI: \_\_\_\_ Last Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Telephone: (     ) \_\_\_\_\_ - \_\_\_\_\_ FAX: (     ) \_\_\_\_\_ - \_\_\_\_\_

Email: \_\_\_\_\_

My check is enclosed

Charge my:     MasterCard     Visa     American Express     Discover

Account Number: \_\_\_\_\_

Expiration Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Name on Card: \_\_\_\_\_

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**In Honor Of:**

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Get Well     Thank You

Other: \_\_\_\_\_

Name (Last, First) \_\_\_\_\_

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**How Shall We Sign the Card?**

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## BP—Model Employer

**B**ritish Petroleum Pipelines of North America received the Chapter's 2004 *Employer of the Year Award* in recognition of BP's spirit of inclusiveness and diversity in the workplace.

Charlie Dameron nominated his employer because he feels that his life is under control because BP gave him the opportunity to continue working, and thereby make his life with MS as normal and productive as possible.

If you know an employer who has made significant contributions toward hiring and retention of employees with MS, please let us know. Call Pam Hirshberg at 1.800.FIGHT.MS or email [ms@cal.nmss.org](mailto:ms@cal.nmss.org) to share how the company has enhanced employment opportunities for someone with MS, and serves as a role model in advancing disability rights.

**Southern California Chapter**  
2440 S. Sepulveda Blvd., Suite 115  
Los Angeles, CA 90064  
310.479.4456

**Inland Empire Field Office**  
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909.307.3388, 800.752.1773

**Coachella Valley Field Office**  
73710 Fred Waring Dr, Suite 103  
Palm Desert, CA 92260  
760.776.5740

**Antelope Valley/Santa Clarita Valley Field Office,**  
1669 West Avenue J, Suite 309  
Lancaster, CA 93534  
661.945.9111

**Kern County Field Office**  
1800 30<sup>th</sup> Street, Suite 105  
Bakersfield, CA 93301  
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National Multiple Sclerosis Society  
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