In 2002, the Society teamed up with its French counterpart to hold a ground-breaking scientific workshop on the topic of nervous system repair. At that time, it was an emerging MS research area with little consensus on whether promoting repair in MS through a cell- or drug-based therapy was even feasible.

Through this collaboration over 100 scientists and clinicians were brought together to discuss whether repair was possible in MS and the likely treatment strategies. This discussion catalyzed the Promise 2010 Nervous System Repair & Protection Initiative and provided a critical step forward in the funding of four international collaborative research teams—led by Dr. Peter Calabresi, Dr. Ian Duncan, Dr. Charles ffrench-Constant, and Dr. Gavin Giovannoni—who received an investment of more than $15 million over a 5-year period.

The Society’s efforts through Promise 2010 have altered the research landscape and accelerated the development of nervous system repair therapies and related strategies.

Some of the outcomes from this initiative include:

- Society funds were leveraged to bring millions of additional funds to nerve repair research.
- New therapeutic targets were identified, accelerating drug discovery for nerve repair.
- Early tests of repair strategies in MS models have shown promising results.
- Clinical trials using cell therapy or drug treatments are underway.
- We engaged hundreds of the brightest minds in MS research to the repair field, and trained scores of promising young investigators who will help carry the work forward.
- The entire field was advanced through published outcomes in more than 180 research papers.
- The initiative jump-started a field that previously was untapped. Through the work of the four collaborative teams, we now know that repair in MS is possible.

continued on page 6 >
Meet Chapter President Susan Bradley

On May 10th, the Board of Trustees and National President Cyndi Zalieboylo named Susan Bradley the new President for the Southern California & Nevada Chapter. Susan is a familiar face in the MS community. She started at the Society in 2005 as VP of Regional Operations and was promoted to Executive VP in 2010. Susan has an MBA from USC and great leadership experience in both the for-profit and nonprofit worlds. She began her career with Xerox sales management, and then spent 15 years in the banking and financial services industry. Susan then moved into the nonprofit world, where she served as executive director of the Stroke Association for three years, before coming to the National MS Society.

Susan has helped to grow Chapter revenue and expand services, and led the successful integration of the Chapter’s regional markets in Channel Islands, the San Joaquin Valley and Nevada. She has created meaningful partnerships and relationships with world-class community health resources to embrace MS as part of their focus. In fundraising, Susan helped revitalize Bike MS, grow Walk MS revenue outside of the Greater LA market, as well as cultivate and steward foundations and major donors. Susan has been a champion for those in underserved communities, and a leader in moving us forward in rural outreach and telemedicine. Susan said, “As we move forward into FY ’13, I look forward to building upon the successes we’ve had in 2012. We’ve experienced growth in many of our key fundraising campaigns; offered popular programs like “Living Well with MS” online so that people with MS may access these valuable resources no matter where they live; and celebrated MS research advances, including the recent FDA approval of the second oral treatment for relapsing MS.”

New Oral Drug Therapy to Treat MS

BREAKING RESEARCH NEWS — FDA Approves Oral Teriflunomide – Brand Name Aubagio®— as Disease-Modifying Therapy for Relapsing MS

The U.S. Food and Drug Administration has approved teriflunomide once-daily pills (Aubagio®, Genzyme, a Sanofi company) to treat relapsing forms of MS. This is the second oral disease-modifying therapy approved for the treatment of multiple sclerosis. The therapy is expected to be available for prescription by October 1, 2012 in the U.S.

“We are greatly encouraged to see a new oral therapeutic option become available to people living with MS,” advised Bruce A. Cohen, MD, Professor, Davee Department of Neurology and Clinical Neurosciences at Northwestern University’s Feinberg School of Medicine, and incoming Chair of the National MS Society’s National Medical Advisory Committee. “As with any new therapy, the long-term safety of Aubagio will need to be carefully monitored,” he added. Dr. Timothy Coetzee, Chief Research Officer at the National MS Society agreed, “With the collaborative research underway around the world today, this is an extremely hopeful time for anyone who is diagnosed with MS.”

Milestones is MS Research

1950: First survey of MS in US and Canada
1965: First MRI brain scans in MS
1980: First MS oral therapy (Gilenya)
1981: First MRI brain scans in MS
1989: Discovery of natural myelin repair
1993: Betaseron Approved
1995: $49 million
2010: First MS oral therapy (Gilenya)
2012: $760+ million
1989: $186 million
1965: $7 million
Steve Yoken Paints the Town

As a long-time supporter of the National MS Society, Steve Yoken is no stranger to MS. He began contributing to the Society after graduating from law school in 1979 and soon took on a leadership role by joining the Chapter’s advisory committee. For Steve, the desire to help those living with MS and find a cure for this unpredictable disease isn’t just a way to give back, it is a personal commitment. Steve’s mother was diagnosed with MS when he was just 5 years old, and at an early age it impressed upon him the need to help other individuals and families living with the daily realities of the disease. To this end, Steve joined Golden Circle in 2010 where he continues to support the Society’s research initiatives as well as local programs and services.

As a partner at Snell & Wilmer in Las Vegas, where he practices commercial real estate law, Steve has also leveraged his business connections to make a difference. When the firm began hosting an annual Paint the Town art exhibit and fundraiser to benefit local charities, Steve jumped at the opportunity to connect his friends and colleagues to an organization close to his heart. This year’s event, entitled “Moving 4ward,” was held on May 11th on the top floor of the firm’s Las Vegas office and featured original artwork by 10 up-and-coming artists from around the world. Each year a portion of the event’s proceeds are directed to charity and this year nearly $7,000 was raised to support the Southern California & Nevada Chapter. As Steve put it, “The National MS Society is a fantastic organization and provides great support to research for a cure and helps people with MS. I hope my contributions will help find a cure.”

Toast to the Cure!

On April 14th, Chapter Trustee and National Board member Kim Phillips and her good friend Sally Turvey hosted a reception at The Margerum Tasting Room at The Wine Cask Restaurant in Santa Barbara. The attendees gathered to learn more about the Society’s NOW campaign. NOW, which stands for No Opportunity Wasted, is the Society’s $250,000,000 research initiative that seeks to Stop MS, Restore function that has been lost because of MS, and End MS forever. The evening was host to 40 people and raised nearly $50,000 in gifts and pledges. Chapter President Susan Bradley remarked how exceptional it felt to have a committed group gathered for such an important reason: to raise critical dollars to fund more MS research. Kim, who was diagnosed with MS in 1986, shared her 26-year journey with MS and why funding more research is crucial — “Time and money, coupled with the best technology, the finest scientific minds from around the globe and a diverse portfolio of research projects will help us achieve the three goals of the NOW campaign. Every dollar makes a difference to help us achieve a world free of MS. The Southern California & Nevada Chapter wishes to thank Kim Phillips and Sally Turvey for graciously hosting this successful reception, and to Doug Margerum for donating his delicious wine and for lending his tasting room to house this fantastic event.
Meet the Society’s Patrons

The Southern California & Nevada Chapter’s permanent donor wall honors many generous individuals, families, foundations and corporations that have directly helped people with MS through the Chapter’s programs and services, while advancing the Society’s goal to be a driving force in MS research, relentlessly pursuing prevention, treatment, and ultimately the cure. Meet a few of the Society’s Patrons, who have individually contributed $50,000 to $249,999.

Sue Kopelove Meltzer & Ruth Lynn Kopelove Sobel

“We believe camaraderie, social activity, education and physical activity are tantamount to providing a full-life experience for MS clients. The Marilyn Hilton MS Achievement Center accomplishes this and much more for so many people! We are proud to have provided the beginning capital contribution to assist in building the center in loving memory of our sister, Nancy Kopelove Siegel, and our parents, Ralph and Marian Kopelove.”

— Ruth Lynn Sobel and Sue Meltzer, Honorary Southern California & Nevada Chapter Trustee

Kevin Goetz and The Rhoda Goetz Foundation for Multiple Sclerosis

Kevin Goetz always knew that his mother would be an influential figure who would inspire him to give back to the community in a very big way. Rhoda Goetz was a vital force – a beautiful, smart, working woman who loved to shop and loved to dance. Rhoda lived with progressive MS for 11 years and Kevin remembers how it impacted the entire family. He fondly recalls his mother’s weekly visits to the beauty parlor – it was a ritual that provided her with a social circle and helped to boost her spirit. Kevin said, “Over time, as her condition worsened, it was difficult for my mom to look at herself in the mirror. She was so beautiful and always had a great figure, but being reliant on a wheelchair, she watched herself gain weight and lose muscle tone.” He continued, “When she went to the beauty parlor, she always felt better.”

In 2005, Kevin founded the Rhoda Goetz Foundation and immediately began the Rhoda Goetz Personal Care Program through the Southern California & Nevada Chapter. “With this Program, I wanted to honor my Mom’s stamina and persistence – for putting a good face to something that was really hard for her, something that was really debilitating.” The Program provides both in-home chore service as well as personal care services for men and women including: hair, skin, nail care and massage; customized self-care assessment/evaluation and coaching; and educational wellness and lifestyle programs. These services help boost confidence, retain independence, regain control over personal care and give a sense of empowerment over physical changes due to illness.

In addition to establishing the Personal Care Program, The Rhoda Goetz Foundation supports MS research that is aimed at alleviating progressive MS, specifically Dr. Steven Goldman’s research at the University of Rochester Medical Center. Kevin said, “I know that we can better understand how and why this disease is caused. I think the discoveries that we make in our research will uncover clues to a whole host of other autoimmune diseases.”
“When I got involved with the National MS Society, I was intent on raising money for MS research. As I got more involved, I became more aware of all the programming the Southern California & Nevada Chapter offered for people with MS like the day wellness programs at The Marilyn Hilton MS Achievement Center at UCLA and scholarships for high school students, who either have MS or a parent with the disease. Multiple sclerosis impacts the whole family, and I appreciate and support the Society’s approach to aggressively funding MS research while providing funding for essential programming to help people live well. I feel proud to have raised more than $1,000,000 to benefit this worthy organization.”

— Sheri Mills Safan, Southern California & Nevada Chapter Trustee

“When you have multiple sclerosis, sometimes it’s hard to talk about what it is and what it can do. The symptoms are varied and it affects people so differently. It took me some time to get officially diagnosed with MS, and it was a very frustrating experience. So much about living with MS is difficult, but it was wonderful to feel so healthy and strong during all 5 of my pregnancies.” It has long been common knowledge that pregnant women with multiple sclerosis experience a sharp drop in the disease’s symptoms during the course of their pregnancy.

“When I learned about the research Dr. Rhonda Voskuhl was conducting at UCLA with the drug estriol, I knew it was something I wanted to help fund. If Dr. Voskuhl’s research could bring a new, inexpensive and effective drug to market to help alleviate the complex symptoms of MS, then I know I will have made my mark against this disease.”

— Genie Riordan Mulé

“I joined the Chapter shortly after our daughter was diagnosed with MS over 20 years ago. We needed to learn about the problem and be part of the solution. The Society helped with both. We’ve had access to the top research and researchers, and we’ve been able to advance that research through our contributions to Golden Circle and the Society’s research campaigns.

For the past eleven years we have been able to raise funds, friends and awareness through the annual MS Charity Bridge Tournament. It is our belief that all of us can involve others in the cause by including them in activities we enjoy and raising money at the same time. We are committed to activism on behalf of the MS Society and our daughter. We are grateful to be able to do so in a meaningful way and through the leading MS organization in the world.”

— Fern Seizer, Southern California & Nevada Chapter Trustee

Visit the Chapter’s “Virtual” Donor Wall at nationalMSsociety.org/cal to read additional donor stories and look for more stories featured in the next issue of this newsletter.
Gavin Giovannoni, MD, PhD

Dr. Giovannoni just received a new grant for $779,538 over 3 years to develop a new method to measure the effects of drugs that limit damage to nerve fibers in MS.

The initial effects of MS result from damage to myelin, the material that surrounds and protects nerve fibers, in the brain and spinal cord (central nervous system, CNS). Nerve fibers that have lost their myelin coating may also be damaged and destroyed, leading to long-term deficits in people with progressive forms of MS.

Following up his studies as a team leader in the National MS Society’s Nervous System Repair and Protection Initiative, which was funded by the Promise 2010 campaign, in this research project Gavin Giovannoni, MD, PhD, is investigating whether the amount of neurofilament (NF) protein in the cerebrospinal fluid (CSF) that bathes the CNS reflects the effects of drugs that may prevent nerve fiber destruction. NF protein is released into the CSF in conditions that cause nerve damage, including MS. Dr. Giovannoni and colleagues are comparing the levels of NF proteins in the CSF of two groups of people with early secondary progressive MS. One group is treated with oxcarbazepine, a drug used to treat epilepsy and that reduces nerve damage in an animal model of MS. The other group receives a placebo. Both groups are continuing their current treatments with interferon beta or glatiramer acetate.

The results of this research could provide a new way to measure how effective drugs that may limit damage to nerve fibers are and could show that one such drug may be useful for treating progressive MS.

continued from page 1

A number of the outcomes from Promise 2010 continue to advance as part of the Society’s new research campaign called NOW: No Opportunity Wasted. This new research campaign is a bold initiative to raise $250 million by 2015 to stop disease progression, restore lost function, and end MS forever.

This comprehensive research approach is demanded by a complicated disease. Our research strategy focuses on the entire research continuum—from the academic bench, to translational work, to clinical trials, to the FDA for approval and ultimately to the clinic and the patient. We believe this integrated approach will support the advancement of the work from Promise 2010. The lessons learned in the area of nervous system repair and protection from Promise 2010 became the building blocks for the “Restore” focus of the NOW Initiative.

This continued advancement of MS research will take the collaborative efforts of many scientists and clinicians, the generosity of countless supporters, and people with MS who will participate in clinical trials of promising new therapies to ensure that the dream of restoring function in MS through nerve and myelin repair comes ever closer to reality. As the Society’s Chief Research Officer Dr. Timothy Coetzee pointed out regarding nerve and myelin repair, “It’s no longer a matter of if, but when. This future can’t come fast enough for people with MS!”
Named for the Society’s founder Sylvia Lawry, the Lawry Circle honors donors who have informed the Society of their intention to help create a better future for the MS community through their will, trust or estate plans.

Planned and deferred gifts provide a strong foundation of funding for the Society. Because all gifts represent an expression of lifetime commitment to the Society, there are no minimum gift levels and membership is for life. Please inform the Society if you have named the National Multiple Sclerosis Society, Southern California & Nevada Chapter in your estate plans by calling Kate McIntosh, Vice President of Development at (310) 479-4456 ext.66124.

Cruising Toward a World Free of MS

Passionate. Dedicated. Strong. After five minutes of speaking with Teri Beardsley, it is impossible not to notice how she exudes these three qualities. With more than 30 years of involvement with the National Multiple Sclerosis Society, it is clear her conviction has not wavered. “I first became involved with the MS Society in 1978, when my oldest brother was diagnosed,” Teri explains. She goes on to detail the progression of two more family diagnoses that included her younger brother as well as her husband, and, eventually, the loss of these three important men in her life.

The concept of the Dream Cruise came out of Teri’s love for classic cars and also her awareness that there was not enough fundraising for MS research. “I wanted to do something to help. There are so many events in the car show world and so I came up with the idea to do a car show with all of the money going to MS.” Teri and her mother run the event themselves, going door-to-door for vendor donations. The Dream Cruise started in 2003 as a part of a Walk MS event in Upland with only 67 cars. In 2012, Teri reported there were over 200 cars and over $7,000 was raised. This year, Teri requested that all funds raised through the Dream Cruise be directed to Golden Circle and designated to support the Society’s scholarship program.

Teri has made it very clear; she is determined to provide help to as many individuals and families with MS as possible. She said this is because of her own experience receiving support from the National MS Society. “It was so nice just to have someone to talk to, someone to listen to me. The MS Society is so great about supporting the families of individuals with MS as well as the individuals themselves. Knowledge is power, and that was my medicine when my brothers were alive.”

In 2006, the National MS Society, Southern California & Nevada Chapter established a scholarship program to help highly qualified students who have been diagnosed with MS, or who have a parent with MS, achieve their dreams of going to college. To date, we have awarded over $200,000 in scholarships to 129 students from various backgrounds and regions within our Chapter. This year we awarded scholarships ranging from $1,000 to $3,000 to 22 college-bound students, all of whom are entering their freshman year at the start of this fall at the college or university of their choice. The Chapter congratulates this diverse group of outstanding students and wishes them the best in their future academic endeavors.

2012 Scholarship Fund

Brianna Kaplan, 2012 Scholarship Recipient

Cari Logston, 2012 Scholarship Recipient
New Inland Empire Office Now Open!

The Southern California & Nevada Chapter is proud of the strong presence it has built in Inland Empire communities over the past decades. We are excited to announce that a brand-new regional office in Ontario is now open for business.

This office, staffed by new Community Development Manager Crystal Britt and supported by Inland Empire Regional Director Debra Gruen, will allow the Chapter to provide more tailored support to those with MS living east of Los Angeles. As Debra Gruen expressed, “We are truly looking forward to being back in the Inland Empire to reconnect with our community partners and provide an array of programs and services for people living with MS and their families.”

Golden Circle Committee
Julie Kaufer, Esq., Chair
Rhona Bader, Paul M. Mahoney, Esq., Pam Maron,
Stanley E. Maron, Esq., Jamey Power, Kim Phillips,
Sheri Safan, Sue Schroeder, Fern Seizer, Timur Tecimer

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Jeanette Chian, Director, Channel Islands Region
Debra Gruen, Director, Inland Empire Region
Kim Kotrla, Director, San Joaquin Valley Region
Linda Lott, Director, Nevada Region
Diane Sant, Development Manager
Danielle Katayama, Development Coordinator

If you are interested in becoming a Golden Circle committee member or would like more information about the Golden Circle campaign, please contact Elicia Lopez, Development Director, at (310) 479-4456 ext. 66111 or elicia.lopez@nmss.org.

National MS Society
Southern California & Nevada Chapter

The Southern California & Nevada Chapter has eight offices serving 19,000 people with MS and their loved ones in Southern and Central California and Nevada. For more information, call (800) 344-4867 and visit www.nationalMSsociety.org/cal.