



Commit to the Cause. Commit to the Care. Commit to the Cure.

Volume VI, Summer 2009

Sometimes Feeling Good on the Inside, Starts on the Outside



Rhoda Goetz

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. When Rhoda was diagnosed, the family

turned to the National MS Society to learn more about the disease. Soon after, Kevin began supporting the Southern California Chapter through the Dinner of Champions. He has also participated annually in Walk MS for over 20 years. In 2006, Kevin joined the Southern California Chapter board of trustees and became a member of The Golden Circle. As Kevin learned more about the organization, he was impressed with how responsive the Society was, and also convinced, more than ever, of the importance of making resources accessible for everyone with MS.

Understanding that living with a chronic illness can make even the simplest daily tasks challenging, Kevin created *The Rhoda Goetz Foundation* in 2005, and then

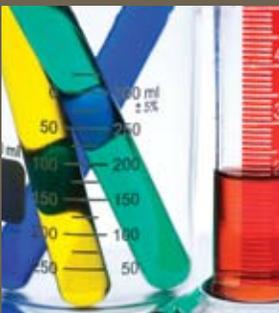
worked with the Chapter to establish the first of its kind *Rhoda Goetz Personal Care Program* in memory of his mother. The Program aims to help people with MS maintain healthy personal care practices and support quality of life, self-esteem and in-home care.

Kevin 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

continued on [page 6 >](#)



Rhoda Goetz and Kevin Goetz



Promise 2010 Update
Page 2



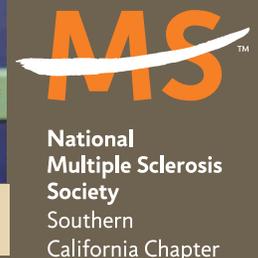
GC Member Stories
Page 3 & 7



Maximize Your Gift
Page 3



Chapter Donor Wall
Page 4 & 5



Countdown to 2010

To Repair and Protect: A Great Scientific Collaboration



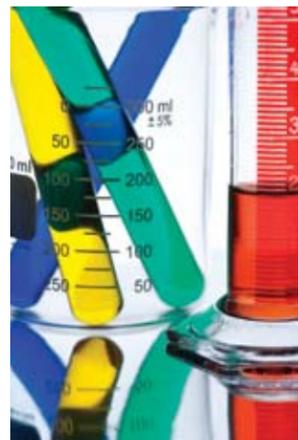
L to R: Dr. Peter Calabresi, Dr. Gavin Giovannoni, Dr. Charles ffrench-Constant, and Dr. Ian Duncan

For anyone interested in MS, the Nervous System Repair & Protection in MS Conference held in New York City in January 2009 was absolutely historic. Of the four Promise: 2010 initiatives, this one involves the most researchers, at the most labs, in the most universities worldwide.

Dr. Charles ffrench-Constant, of the universities of Cambridge and Edinburgh, spoke of how he overcame challenges to collaboration: "I would not have imagined, when we started this, how difficult it is to get one university to give money to another university." ffrench-Constant hired a project management company that specializes in scientific collaborations to make sure that information and money would get transmitted on time, allowing the science to move forward.

"The questions these days are so big, you need collaborations," said Patricia O'Looney, PhD, the Society's Vice President of Biomedical Research.

When a collaboration does get rolling, it can really roll. The Repair Initiative consists of four teams that are each working on several projects. (In addition to Dr. ffrench-Constant, they are led by Dr. Peter Calabresi of Johns Hopkins University, Dr. Gavin Giovannoni of Barts and The London School of Medicine and Dentistry, and Dr. Ian D. Duncan of the University of Wisconsin at Madison.) Each of the four teams has spawned new experiments and swept in more researchers. At Hopkins, for example, 22 people were receiving Promise: 2010



funding, yet 62 people were participating — meaning the MS community was, in effect, getting 40 brains for free. "This has been a great success in terms of leveraging your money," Calabresi said.

Attendees at the January conference signed nondisclosure agreements so they could discuss ongoing experiments prior to publication in scientific journals. Duncan shared preliminary data showing remarkable demyelination (damage to the myelin coating on nerve fibers) and remyelination (myelin repair) — starkly visible even to the untrained eye in microscope slides — in a small number of lab animals.

The flip side of sharing exciting results is sharing disappointments. To Emily Potter, PhD, a member of the Calabresi team, the chance to speak freely with colleagues about stumbling blocks was one of the most valuable elements of the conference. "Reading journals isn't enough to keep informed. To get things done, negative data can be just as important as positive data, but there's a bias for positive data in the medical literature," Potter said. "So it is nice to be able to discuss these things freely."

"It's the sort of thing that gets you excited, that keeps me awake, Duncan said."

You may restrict Golden Circle gifts to Promise: 2010 or specifically to one of its four targeted initiatives. If you would like to make a gift to support these vital research projects or if you are interested in attending the MS Conference in January 2010, please contact Kate McIntosh, Vice President of Development at (310) 479-4456 ext. 124. The Conference is open to the public. To read more about the information above and other updates, please visit www.nationalMSSociety.org/research.

On the Path to Clinical Trials

When the topic is research, people living with MS want to hear two words: clinical trials. Though the Nervous System Repair & Protection Initiative was charged with just laying the groundwork for clinical trials by 2010, trials are already beginning.

"You can...if you think you can"

"You can...if you think you can" reads a plaque that hangs prominently in the Graves' home in Santa Barbara. It's a motto that Marge, Don and their five children, Brian, Lee, Steve, Ann, and Paul, choose to live by. "These words never became more important than when Ann was diagnosed with multiple sclerosis in 2000," said Marge. "Life can be hard, but like the little engine that could, you keep on going." Indeed she did! Marge started volunteering at the Chapter's Santa Barbara office in 2002; Marge and her family raised \$14,000 with the Marathon Strides program in 2004; participated in Walk MS for the last 7 years; and joined The Golden Circle in 2004.

Thanks to Marge's volunteer work, the Southern California Chapter has discovered valuable community resources for people with MS and their families. Vista Del Monte, Cottage Rehabilitation Hospital, Community Memorial Health, and Sansum Clinic are just a few of the local facilities offering new exercise programs for people with MS and other disabilities. With new classes always on the horizon, Marge feels that her work will never be done. When asked why she continues to volunteer, she responded, "I've always been involved as a volunteer in many organizations. MS is in the family. *Fitness for All* is a project that I find fulfilling as a person and it helps the community."



Marge Graves and daughter Ann Graves wearing their MS Marathon Strides shirts at the Santa Barbara Half Marathon in November 2007

At the time of Ann's diagnosis, her neurologist stressed that exercise is critical for people with MS. The Graves family agrees wholeheartedly. Currently, Marge leads the *Fitness for All* initiative for Santa Barbara and Ventura County. Marge uncovers fitness centers, yoga classes, and swimming facilities suitable for people with multiple sclerosis. Armed with an extensive checklist, Marge starts the screening process as soon as she pulls into the parking lot. She checks the number of handicap parking spaces and the accessibility of the entrance. Her initial test includes many details such as the number of accessible bathrooms, temperature of the pool, and the space between exercise machines. If the facility meets ADA requirements, Marge participates in the classes being offered, and then interviews the facilitators to check their credentials. She explained, "One surprise of this project is that many instructors don't know anything about MS. My time is spent teaching them the basics. My role turns to public relations as we discuss MS and the National MS Society."

THE 2009 GOLDEN CIRCLE SOUTHERN CALIFORNIA CHAPTER CARES CHALLENGE

Generously sponsored by
Golden Circle members
Sharon and Hal Lampert

Longtime, loyal friends of the Southern California Chapter, Sharon and Hal Lampert, have generously pledged \$250,000 to The 2009 Golden Circle **Southern California Chapter Cares Challenge** to encourage \$500,000 in outright giving this summer.

If overall Golden Circle gifts and pledges total at least \$500,000 by **September 15, 2009**, the Lampert family will contribute an additional \$250,000 to ensure the Chapter receives a minimum of **\$750,000!** Every gift or pledge regardless of restriction or amount will count toward the Challenge!

Your gift is so important to the Southern California Chapter. Please consider making your gift to The Golden Circle now to maximize the power of your giving.

Meet the Society's Angels

The Southern California 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 the Society's Angels, who have contributed \$500,000 to \$999,999.

California Community Foundation

"The donors, staff and board of the California Community Foundation are proud to partner with the National MS Society to improve the lives of our most vulnerable populations. It is our honor and privilege to facilitate the philanthropy of donors in Los Angeles and support organizations doing such valuable work."

— Terri Mosqueda, MPA, Donor Relations Officer



Change a Life Foundation

"Change a Life Foundation is proud to partner with such a wonderful organization that provides programs, services, education and advocacy to assist individuals and move them to a greater independence, mobility and self sufficiency in their lives. We appreciate the opportunity to fund such a worthwhile organization. Change a Life Foundation invests our grant allocations to organizations and their clients as a financial bridge of hope and humanity to those who have nowhere else to turn and need assistance crossing through the challenges of life. Supporting the 64 grants with \$640,000 to the Southern California Chapter, National MS Society has been an amazing experience and made a significant impact. Together we changed hundreds of peoples lives!"

— Lisa C. Fujimoto, Executive Director



Entertainment Industry Foundation

"The Entertainment Industry Foundation is proud to support the crucial work of the MS Society year after year. The Dinner of Champions is a hopeful evening that reinforces why we stand with you as your wonderful organization redefines what it means to live with MS. We are passionate about our support of the National MS Society because we believe it is vital for the organization to continue moving forward in its mission."

— Lisa Paulsen, President and CEO, Entertainment Industry Foundation



New Wave Entertainment

"We are passionate about our support of the National MS Society because we believe it is vital for the organization to continue moving forward in its mission."

— Paul Apel, CEO, New Wave Entertainment



new wave
entertainment

In Memory of Julie Power

"Our family knows firsthand the devastating effects of MS and their impact on individuals and their families. Our loving mother, Julie Power, lost her battle with MS in 2002. Since then she has been our guiding inspiration in giving back to the MS Society. Our family believes that the MS Society has taken the lead in collaborative research and innovative approaches that will ultimately lead to the development of better treatments for patients living with MS. We applaud and support the National Multiple Sclerosis Society for being the organization for people with MS."

— The Power Family



Regal Entertainment Group

"It has always been a priority at Regal to give back and support the communities in which we live. Since 1995 we have proudly supported the Dinner of Champions in their ongoing efforts to raise funds to combat MS. Through the efforts of industry veteran Tom Sherak, this dinner has evolved into one of our industry's most significant and meaningful events. I commend the MS Society on their continued efforts to treat and find a cure for MS."

— Greg Dunn, President and COO of Regal Entertainment Group



Revolution Studios

"For 35 years, the National Multiple Sclerosis Society, Southern California Chapter's Dinner of Champions has consistently been one of the most highly visible events in Los Angeles. The Dinner of Champions is always an inspiring event because it brings together so many industries to support vital programs and services as well as advance critical MS research. Revolution Studios is proud to support the National Multiple Sclerosis Society."

— Joe Roth, Founder, Revolution Studios





Named for the Society's founder Sylvia Lawry, the newly rebranded 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. Please call Kate McIntosh, Vice President of Development at (310) 479-4456 ext. 124 if you have named the National Multiple Sclerosis Society, Southern California Chapter in your estate plans. There are no minimum gift levels required to be a member of the Lawry Circle.

Rhoda Goetz Personal Care Program continued from page 1

muscle tone." He continued, "When she went to the beauty parlor, she always felt better. With this Program, I want to honor her stamina and persistence — for putting a good face to something that was really hard for her, something that was really debilitating."

The Program provides personal care services for both 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.

The Program was designed for individuals living with MS who could not otherwise afford or manage their personal care due to mobility issues, difficulties with transportation and financial limitations. In January 2007, the Rhoda Goetz Personal Care Program was launched at the *Center for Optimal Living with MS* at Rancho Los Amigos in



Rhoda Goetz

arrange for transportation or for someone to transfer me in order to have my hair done. Gerri comes right to my house and has been cutting my hair for two years now, thanks to the funding from the Rhoda Goetz program. I'm doing my best to live with this disease and this program is just one way I can manage my life."

Since its first three years, the Program has gained huge momentum in facilities across California and continues to grow — with the Society's New Jersey Metro Chapter establishing the Program this year. By using the current program as a prototype, Kevin hopes to someday see the Rhoda Goetz Personal Care Program across the country.

"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."

Downey. The facility includes adaptive salon equipment to accommodate Center members using wheelchairs. In 2008, the Program expanded to reach individuals with MS in skilled nursing facilities, including Hillcrest Care Center, Park Ventura, Woodland Care Center and Glenwood Gardens.

Gerri Woessner, a licensed cosmetologist with Have Shears will Travel, visits clients in their homes to cut and shampoo their hair. Gerri, who has a good friend with MS, understands how providing small services like these can impact one's outlook on life. Charlotte, who was diagnosed in 1985, gets her hair cut regularly from Gerri. Charlotte said, "This program is so beneficial because it means I do not have to

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 at 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."

Gifts made to The Golden Circle can be restricted to support the Rhoda Goetz Personal Care Program. Please contact Kate McIntosh, Vice President of Development at (310) 479-4456 ext. 124.

A Mother's Courage, a Family's Determination

By Dina Tecimer and Timur Tecimer, Chapter Trustees

When our mother, Lailee Bakhtiar, MD, experienced the onset of MS symptoms in 1984, little was known about this disease. In the early 1980's, there were no MRI's or definitive tests for diagnosis, no FDA-approved drug therapies and few treatment options. At the time, our mother was an



Dina Tecimer and Timur Tecimer

active, accomplished physician with a private practice in Brentwood, on staff at Cedars, UCLA and St. Johns, and traveling physician with Zubin Mehta and the LA Philharmonic. Yet, she, better than most, understood the severity of her diagnosis and chose to meet her future head-on. She has always been a positive, courageous, independent woman and an inspirational force in our lives. So her determination to live life to the fullest in spite of her MS didn't surprise us, but her journey has been challenging.

From the beginning, we have dealt with this disease as a family; accompanying our mom to doctor's appointments, driving her to physical and occupational therapy sessions, coping with the side-effects of clinical drug trials and minimizing the impact of her eventual loss of independence and mobility. Through it all, the MS Society has been a consistent resource of programs, services and specialists, and more importantly, a tangible source of hope, as new drugs were developed in the late 1980's and 1990's to decrease the symptoms of MS.

Never a group to sit back, we are a hands-on family and needed to roll up our sleeves and dig in. We wanted to do something about MS right away. Our mother joined the

Chapter board of trustees in 1993, and we have followed in her footsteps (Dina in 1996 and Timur in 2008). We have attended Chapter events, joined the board of The Marilyn Hilton MS Achievement Center at UCLA (Dina 2003 – present), started a workplace computer donation service, and have advocated with one voice to put MS at the top of everyone's agenda.

From the beginning, we wanted to raise money for research. We became drawn to The Golden Circle, in particular, because we liked the idea of designating our gifts 100% to research, an opportunity specific to The Golden Circle campaign. We have been Golden Circle members for more than 12 years, and joined the Board's Golden Circle sub-committee (Dina chaired the committee 2001-2003), with energy and gusto. We have hosted fundraising and networking events; have asked our friends, co-workers and others to help us support MS research; and have continued to be part of a passionate group of people committed to finding a cure for MS, while providing quality programs and services for those living with the disease.

From our point of view, the more money going directly to research, the more treatment drugs fill the pipeline and the faster researchers will find a cure. Over the years, The Golden Circle has also allowed us to become supporters of

"From our point of view, the more money going directly to research, the more treatment drugs fill the pipeline and the faster researchers will find a cure."

The Marilyn Hilton MS Achievement Center at UCLA. We experienced first-hand the difficulty in locating specialists and resources, and were impressed to find a Center that expertly combines all these services in one location, similar to "one-stop shopping."

Although our fight against MS today is different than it was 26 years ago, we still have an uphill battle. As our mother faces the daily complexities of MS and takes on each new challenge with grace and dignity, never giving up hope, she continues to inspire us to take on the disease, with all the energy we have. We owe it to her and all those living with MS to do everything we can to put it to a stop.



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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, Senior Development Manager, at 310.479.4456 ext. 111 or elicia.lopez@nmss.org.

National MS Society Southern California Chapter

The Southern California Chapter has seven offices serving 14,500 people with MS and their loved ones in Los Angeles, Ventura, Santa Barbara, San Luis Obispo, Riverside, San Bernardino, Inyo, Kern, Fresno, Kings, Madera and Tulare counties. For more information, call (800) 344-4867 and visit www.nationalMSsociety.org/cal.

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