

## A Helping Hand When It's Needed Most

Multiple sclerosis creates a range of challenges that can result in short-term financial crises, difficulty obtaining critical equipment, and diminished capacity to pay for MS-generated needs. The National MS Society's Financial Assistance Program offers guidance, leverage and resources to help contain the financial impact of MS.

Becky Griffith was diagnosed with MS in 1991 while working as a registered nurse. Slowly the disease robbed her mobility. Last year, Becky contacted the Southern California & Nevada Chapter because she needed assistance to purchase a scooter. Her old scooter was no longer working and she had been muddling through without one for a couple of years while she battled her insurance company. Becky's son was getting ready to graduate high school, and she realized that she'd be unable to attend the ceremony on her own. The Chapter was able to assist with the co-pay. Afterward, Becky wrote, "I never thought it would feel so good to be able to ride in a scooter. Without the help of the MS Society, I would not have been able to handle my



Byron & Becky Griffith

son's graduation...It's more than a 'scooter' to me — it's the hope of independence, family memories, and feeling like someone cared enough to help."

Becky is one of 500 individuals and families to whom we provided a helping hand in 2012 alone. The Chapter funded over \$270,000 in direct financial assistance to address the greatest needs, including emergency rent, utilities, transportation, durable medical equipment, home modification, care management and more. The program, based on financial need, is designed to help access these needed services that are not available through other resources or insurance:

### Medical Care

- MS Physician Consult program: Funding for a one-time consult with an MS specialty neurologist
- Physical/occupational/speech therapy: In-home evaluation and follow-up visits for a person who cannot leave home
- Individual counseling/telecounseling sessions with a licensed therapist who is experienced with MS

### Support Services

- Sherak Emergency Fund: For unexpected one-time situations (food, rent, utilities, etc.)
- Durable medical equipment: Share of cost for equipment such as wheelchairs, hand rails, etc.
- Rhoda Goetz Home Assistance Fund: In-home help

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**National  
Multiple Sclerosis  
Society**  
Southern California  
& Nevada Chapter

## Breaking News: Third Oral Therapy Approved for MS

On March 27<sup>th</sup>, the FDA approved Tecfidera™ capsules (dimethyl fumarate, Biogen Idec – formerly “BG-12”) as a first-line disease-modifying therapy for people with relapsing forms of MS. This makes the third oral therapy approved for relapsing MS, and the tenth disease-modifying treatment available in the U.S.



Although its exact mechanism of action is not known, Tecfidera is thought to inhibit immune cells and molecules, and may have anti-oxidant properties that could protect against damage to the brain and spinal cord. The twice-daily capsules were shown in clinical trials to significantly reduce relapses and disease activity on MRIs, and in one trial it reduced progression of disability.



“The approval of Tecfidera is an important expansion of therapeutic options, and increases our ability to find effective and tolerable treatment solutions for individual patients,” said Bruce A. Cohen, MD, Professor, Davee Department of Neurology and Clinical Neurosciences at Northwestern University’s Feinberg School of Medicine, and Chair of the National MS Society’s National Medical Advisory Committee.

## Speeding Treatments for Progressive MS

In the first meeting of its kind, more than 170 MS researchers and clinicians from around the world gathered in Milan, Italy in February to discuss key challenges and strategies to expedite treatments for progressive forms of MS, including those that can halt or even reverse MS progression. Leading experts across a variety of research areas affirmed the importance of working together globally to drive advances in treating progressive MS, as well as a shared optimism that such an investment can yield the results urgently needed by those living with the disease. This landmark meeting was convened by the **International Progressive MS Collaborative**, a joint effort of the MS International Federation and MS Societies of Canada, Italy, Netherlands, United Kingdom, and the United States.

Meeting co-chair Dr. Alan Thompson (University College London) noted that an estimated \$85 million is being invested right now by MS societies around the world, in addition to what pharmaceutical companies are investing in several major clinical trials involving people with progressive MS. Nearly every therapy approved for relapsing MS has been tested, or is now in testing, in people with progressive forms of the disease, including primary-progressive MS and secondary-progressive MS. Up to now, clinical trials involving people with relapsing MS often rely on counting relapses or doing MRI scans to detect immune activity. The fact that there is no easy way to detect progression quickly is one reason why development of therapies for progressive MS is behind. The National MS Society is investing in better ways to detect benefits of therapies for progressive forms of MS. Right now there are large clinical trials going on in progressive MS, including tests of Tysabri®, Gilenya®, Ocrelizumab, and Masitinib.

Timothy Coetzee, PhD, Chief Research Officer at the National MS Society noted, “Having ten disease-modifying therapies available for relapsing forms of MS further motivates us to gather the forces of the global community to make similar strides for people with progressive forms of MS, for whom there are fewer options.”

### Also in the Pipeline

Genzyme has applied for FDA approval of the experimental therapy alemtuzumab, given by a cycle of IV infusions once per year, to treat relapsing MS, based on positive results from several clinical trials. An FDA decision is expected by the end of 2013. Oral and infrequent-dose disease-modifying therapies are just two of many exciting research avenues that address ways to stop MS progression, restore function and end MS forever. Just a few new approaches being explored include potential benefits of the hormone estradiol, adult stem cell transplantation, large-scale clinical trials for progressive MS, trials of agents aimed at protecting the nervous system, and studies of vitamin D and CCSVI (chronic cerebrospinal venous insufficiency).

# Golden Circle Research Receptions

This winter, the Southern California & Nevada Chapter hosted two research receptions for Golden Circle donors and top event fundraisers to hear first-hand from world-renowned MS researchers. Attendees learned about current projects and had a chance to engage in conversation about the future of MS research with two of the best minds in the field today.

The first event, held December 5<sup>th</sup> at the Brentwood Country Club, featured Dr. Gavin Giovannoni of London's Queen Mary and Westfield College. Dr. Giovannoni was a principal researcher in the Society's Promise 2010: Nervous System Repair & Protection initiative and spoke to the significant progress his team, and the three others funded through the initiative, made during the 5-year Promise 2010 study. He discussed a clinical trial made possible through Promise 2010, as well as the development of improved diagnostic tools and a consolidated framework for conducting shorter clinical trials in the future. Over the next three years, Dr. Giovannoni and his team, funded through the Society's MS NOW Research initiative, are looking to develop new ways of measuring drug efficacy in limiting damage to nerve fibers. Society President and CEO Cyndi Zagieboylo thanked donors for the tremendous contributions they continue to make in the area of MS research. The Chapter would like to extend our sincere thanks to the evening's extraordinary co-hosts, Stan and Pam Maron and Fern and Bob Seizer. The event would not have been possible without their generosity in hosting and underwriting this reception.

On February 21<sup>st</sup>, Dr. Stephen Hauser of UCSF presented current breakthroughs in MS research at a reception at the Ritz-

Carlton in Marina Del Rey. He demonstrated how far we have come with diagnostic tools, showing pictures of the very first MRI scans compared to the current multi-colored, high resolution versions; discussed new drugs in the pipeline; and shared his hope that we will have at least 15 disease-modifying therapies available by 2015. He was excited about one of his current studies, a patient data pilot project currently in early stages at UCSF. The project uses an iPad to easily capture patient data to access a patient's complete medical records including test results, MRI scans, etc. all in one location. Most significant is the system's ability to consolidate information from multiple patient records and provide useful trend data which could ultimately help physicians better predict an individual course of MS and select more effective treatment options.

Cultivating new and existing relationships within our community is key to the Chapter's continued ability to provide essential programs and services, fund MS research, and grow the Golden Circle campaign. If you or someone you know is interested in hosting and/or underwriting a salon event at your home, business/country club or other location, please contact Elicia Lopez at (310) 481-1111 or [Elicia.Lopez@nmss.org](mailto:Elicia.Lopez@nmss.org).



Dr. Cynthia McGranahan, Lyle Dawn & Chapter President Susan Bradley



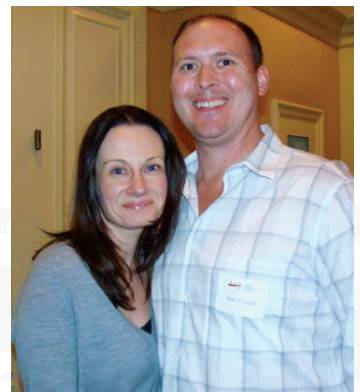
Dr. Stephen Hauser & Dave Power



Julie Kaufer & Elizabeth Cheung



Julie Goldman & Ronnie Fishman



Jeanne Usonis & Mike D'Zurilla

# 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 contributed \$50,000 – \$249,999.

## Julie & Barry Engelman

"It's been 11 years since our son was diagnosed with MS. Immediately, the entire family mobilized to learn as much about this disease as we could and to direct our efforts to supporting the search for a cure. Our daughter, Traci, organized our first LA Walk MS team raising \$22,000 from her home in New York City. Since then our entire family rallied each year to make our MS walk team, and later our Bike MS team hugely successful fundraising efforts raising a cumulative total of one million dollars.

Six years ago we made a personal commitment to Golden Circle and have attended many of the informative events. We have been gratified to learn just how much our efforts have contributed to the cutting edge research that will eventually result in a cure. We feel privileged to hear presentations from some of the world's most prominent MS researchers.

Naturally we would like to see a cure today, but are heartened that eleven years ago there were only three drugs for relapsing remitting MS, and now there are ten with many more in the pipeline. Recently MS was identified as one of the two diseases showing the greatest progress in treatment protocols in the last ten years. We know that much of this progress has been made possible as a result of the collective efforts of Golden Circle contributors."

— Julie & Barry Engelman



Julie, Traci, Jamie, Barry and Eric Engelman

## Joan & Arnold Seidel

"We will find a cure for MS in our lifetime. There are many researchers doing top quality research and the MS Society's comprehensive research portfolio pursues all avenues and consequently few paths have been fruitless. Medical research comes in small steps and can be discouraging but once in a while it can be exciting and successful! We have no idea where or when a breakthrough will happen, but we hope and look forward to a foreseeable future with a cure. We are grateful to the many researchers working hard to get us there."

— Joan & Arnold Seidel



Arnold & Joan Seidel

## Edward Taran

"I first became involved with the National MS Society more than 30 years ago. I saw first-hand what it meant to live with MS and I needed to do something to help. I started by making an annual contribution. Since then, I have watched with anticipation the progress made in MS research. I have been impressed with the Society's holistic approach to research and the extensive peer review process for selecting projects. Over the years I have participated in Walk MS and joined Golden Circle where I continued to fund research through both the Promise 2010 and Fast Forward campaigns. I trust in the caliber of research the Society funds and I'm committed to being part of the solution for all of us with MS who are waiting for a cure."

— Edward Taran

## Jane Lee & Larry Winter

"Jane Lee and I are active with the National MS Society because of my brother David. David was diagnosed with MS at the age of 23. It started with blurred vision and then gradually moved into his ability to walk, and finally had to use a wheel chair. By the age of 35 he was living a nursing home and passed away at age 43.

Ever since his diagnosis and then more after his death, I have always pledged that I would do whatever I could to help raise money to find a cure and also help families who have a loved one who is living with the disease each day.

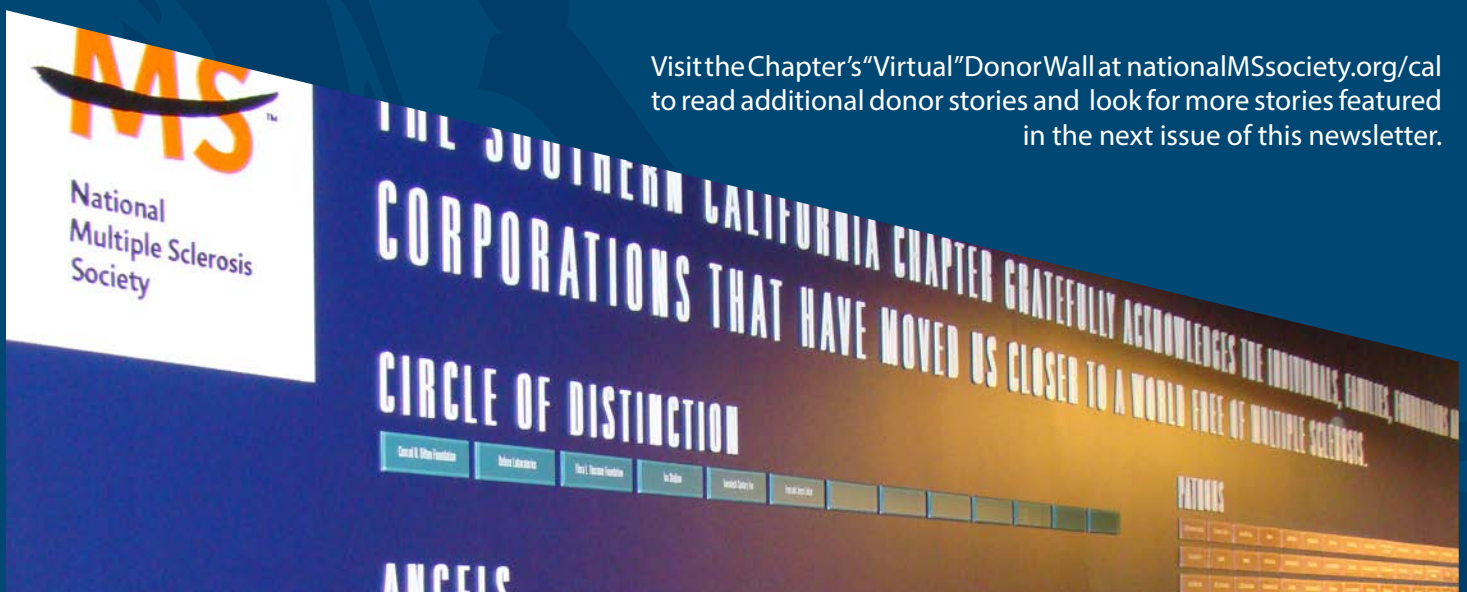
Our involvement includes serving on the board, but also being active by telling others about the Society and encouraging people with the disease to seek help from their local MS office. We have also included the MS Society in our estate plans."

— Jane Lee & Larry Winter



Larry & Jane Lee Winter

Visit the Chapter's "Virtual" Donor Wall at [nationalMSSociety.org/cal](http://nationalMSSociety.org/cal) to read additional donor stories and look for more stories featured in the next issue of this newsletter.



## ...A Helping Hand continued from page 1

for a person experiencing an exacerbation or post-hospital visit who does not have a caregiver

- Rhoda Goetz Personal Care Fund:
  - Beauty/wellness: Access to services to maintain healthy personal hygiene and care
  - Chore service: Light housekeeping for those unable to manage these tasks

### Support for Family Members

- Grisanti Respite Fund: Funding for a licensed home care agency to provide support for a family member who is a full-time care partner and needs time off
- Supporting the Family: For special out-of-the-ordinary family needs (school photos, sports uniforms, etc.)

In addition to its own commitments, the Chapter leveraged an additional \$26,000 in community resources and an additional \$4,000 from Stepping Stones. Stepping

Stones is the Society's nationwide endowment fund for financial assistance to people with MS and disbursed only in conjunction with a chapter's own financial assistance funds and leveraged community resources. This program assists with requests normally larger than that which can be provided by a chapter and community resources alone, and provides the ability to address some of the larger financial challenges faced by people living with MS.

Gifts to Golden Circle may be restricted to support the Chapter's Direct Financial Assistance Programs. Recently, Golden Circle committee member Sheri Safan launched a letter-writing campaign to focus attention on these important programs. Many thanks to Sheri for rallying friends and family to raise more than \$20,000 to support these meaningful services that directly impact families struggling with the financial burden MS may cause.

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## Fund the Need

More than 18,000 people with MS reside in skilled nursing facilities (SNFs) across the United States, and more than half are younger than age 65, with a substantial number in their thirties and forties.

As a partner in MS care, the Southern California & Nevada Chapter works with Hillcrest Care Center in Long Beach, CA to complement the Center's provision of skilled nursing care for the more than fifty residents who have MS. Together, we provide therapeutic exercise and a full range of emotional, social, physical, spiritual, intellectual, and recreational activities. Recently, the Chapter also launched the MSConnect Project, which aims to utilize ever-advancing tablet technology to transform isolation into connection.

The latest advances in touch-screen technology make tablet use much more accessible for people with a wide range of significant disabilities. Mary Ann Holm, MSW, Manager of Clinical Services at the National MS Society explained, "I often visit people with MS at skilled nursing facilities and assisted living communities. Though they are physically challenged, they are still young and vibrant individuals who, like you and I, thrive in environments that



support our intellectual, emotional and social needs. I have seen many slowly disappear into a world of isolation and loneliness. The tablet technology is a bridge back to the world where they once participated. Email, Facebook and Skype are just a few of the applications that can keep the connection alive and various other software programs can keep people intellectually stimulated and engaged."

### How can you help?

- Donate your gently used tablet or iPad to the National MS Society.
- Purchase a tablet or iPad directly for the National MS Society.
- Donate any dollar amount to be used toward the purchase of a tablet or iPad by the National MS Society.

These donated tablets will be distributed to people living with MS in skilled nursing facilities in our local communities. Your contributions will directly impact people living with progressive MS.

# Creating a Legacy for a World Free of MS



Helen Bolsky & Georgette Pagano

Beloved friend and longtime supporter of the National MS Society Helen Bolsky passed away in October 2012. Helen was one of the Chapter's most dedicated Golden Circle members, having

been part of the campaign since its inception in 1993. For almost 20 years Helen directed her giving to support research – in honor of her daughter Debbie who has MS. Helen was widely recognized in the Los Angeles community for her philanthropy. Helen's ultimate gift, her legacy, came in the form of a bequest, as she named the

National MS Society, Southern California & Nevada Chapter as a beneficiary in her will.

Society donors like Helen help create a better future for the MS community through bequests. Naming the Society in your will is the ultimate expression of confidence in the Society's vast work. Anyone can structure their bequest with a specific amount, make the gift contingent, or leave a percentage. Gifts may be restricted for a specific type of research; or it can be earmarked for services, such as emergency funds, scholarships or educational programs. The Chapter's Tax ID and local address are all you need to appropriate your own legacy. For more information please contact Diane Sant at (310) 481-1108 or [diane.sant@nmss.org](mailto:diane.sant@nmss.org).



## What a Difference a Day Makes!

On Saturday, March 16, the Chapter's Kern County staff and volunteers divided into teams for the 4<sup>th</sup> annual MS Service Day in Kern County. The event, designed to complete common household tasks or small home improvement projects for families impacted by multiple sclerosis, has grown quite a bit since it started as a Boy Scout's Eagle Scout project in 2010. This year, volunteer teams helped eight different families – installed grab bars, did yard work, helped with cleaning, performed electrical work, poured a concrete walk way, and repaired a sprinkler. Many thanks to Chevron for sponsoring the project for a third consecutive year. Their generous donation was used to purchase supplies needed to complete these projects.



Volunteers in the community have become so inspired by MS Service Day that they continue to engage in projects beyond the designated day. This spring, they also widened a bathroom door for a woman who uses a wheelchair; built a ramp for another woman who uses a wheelchair; and with help from the local carpenters union, also built ramps to the front and back doors for a man who uses a wheelchair.

For the first time, the Chapter is now offering MS Service Day in Long Beach. In cooperation with Operation Jump Start (a Long Beach community-based nonprofit), volunteers will complete home improvement projects for people with MS in Long Beach on May 18<sup>th</sup>.

# Challenge accepted. Challenge met.

The 2012 Golden Circle Year End Challenge was a tremendous success!

We are thrilled to announce that, for the 5<sup>th</sup> year in a row, Golden Circle donors rose to the challenge posed by the Kenrose Kitchen Table Foundation and the Steve & Caroline Kaufer Family. With the generosity of hundreds of individuals, family foundation and corporations, the campaign met and surpassed the year-end goal of \$550,000, raising nearly \$665,000 via gifts of stock, personal checks, credit cards and cash between 10/1/2012 and 12/31/2012. As a result, the Golden Circle campaign raised more than \$1.47 million in 2012! The contributions from this year-end challenge will assist those living with MS and provide hope through research.

We extend our deepest appreciation to the Kenrose Kitchen Table Foundation and the Steve & Caroline Kaufer Family for their continued support and leadership.



## Golden Circle Committee

**Julie Kaufer, Esq., Chair**

Pam Maron, Stanley E. Maron, Esq., Kim Phillips,  
Jamey Power, Sheri Safan, Sue Schroeder, Fern Seizer

## Golden Circle Staff

**Susan Bradley, President**

Kate McIntosh, Vice President of Development

Elicia Lopez, Development Director

Jeanette Chian, Director, Channel Islands

Debra Gruen, Director, Inland Empire

Kim Kotrla, Director, San Joaquin Valley

Linda Lott, Director, Nevada

Diane Sant, Development Manager

Danielle Katayama, Development Coordinator



Back row: Kim Kotrla, Diane Sant, Elicia Lopez, Susan Bradley,  
Kate McIntosh Front row: Danielle Katayama and Debra Gruen

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 at (310) 481-1111 or [elicia.lopez@nmss.org](mailto: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](http://www.nationalMSSociety.org/cal).

### Channel Islands Office

14 West Valerio Street  
Santa Barbara, CA 93101

### Coachella Valley Office

73-710 Fred Waring Dr., Suite 103  
Palm Desert, CA 92260

### Inland Empire Office

3110 East Guasti Road, Suite 320  
Ontario, CA 91761

### Kern County Office

1800 30th Street, Suite 105  
Bakersfield, CA 93301

### Las Vegas Office

2110 East Flamingo, Suite 214  
Las Vegas, NV 89119

### Reno Office

4600 Kietzke Lane, Suite K-225  
Reno, NV 89502

### San Joaquin Valley Office

7472 N. Fresno St., Suite 210  
Fresno, CA 93720

### West Los Angeles Office

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Los Angeles, CA 90064



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