

# MS CONNECTION NEWSLETTER



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## GET CONNECTED **CALENDAR**

### **Resilience**

June, Las Vegas, NV

[nationalMSSociety.org/CALcalendar](http://nationalMSSociety.org/CALcalendar)

### **Hollywood Bowl**

#### **July 4th Spectacular**

[nationalMSSociety.org/CALcalendar](http://nationalMSSociety.org/CALcalendar)

### **Everyday Matters**

- July, Los Angeles, CA
- Saturday, September 16, Reno, NV

[nationalMSSociety.org/CALcalendar](http://nationalMSSociety.org/CALcalendar)

### **Live Fully, Live Well**

- August, Santa Barbara, CA
- Saturday, September 16  
Los Angeles, CA

[nationalMSSociety.org/CALcalendar](http://nationalMSSociety.org/CALcalendar)

### **Dinner of Champions**

- Thursday, August 24, Reno, NV  
Honoring Anthony Slonim, MD,  
DrPH/President & CEO,  
Renown Health
- Thursday, September 28, Las Vegas,  
NV Honoring Jan Jones Blackhurst,  
Executive Vice President, Public  
Policy & Corporate Responsibility,  
Caesars Entertainment
- Date TBD, Los Angeles, CA

Advance tickets required; contact

[linda.lott@nmss.org](mailto:linda.lott@nmss.org) or

775-827-4257 x66801

### **Walk MS®: South Lake Tahoe**

Saturday, September 16

Camp Richardson Resort-Hotel

Register at [walkMS.org](http://walkMS.org)

### **Exercise and MS**

Mondays June 12-August 28

10 a.m.-12 p.m.

UCLA MS Achievement Center

[nationalMSSociety.org/CALcalendar](http://nationalMSSociety.org/CALcalendar)

### **Bike MS®: Vegas**

Saturday, October 28

Register at [bikeMS.org](http://bikeMS.org)

### **Challenge Walk MS®: Southern California**

November 3-5, San Diego

Register at [challengewalkMS.org](http://challengewalkMS.org)

### **MuckFest® MS**

Saturday, November 11

Register at [muckfestMS.org](http://muckfestMS.org)

### **Walk MS: Bakersfield**

Saturday, November 18

Register at [walkMS.org](http://walkMS.org)

**THANK YOU TO OUR 2017  
WALK MS NATIONAL SPONSORS:**

**Genentech**  
A Member of the Roche Group



**NOVARTIS**

**SANOFI GENZYME**





## A Breakthrough with Your Name on It

In March, the Food and Drug Administration approved a new multiple sclerosis therapy, marking the first-ever disease-

modifying treatment for primary progressive MS and an important new option for people with relapsing forms of the disease (p. 3).

It's a significant milestone toward finding solutions for ALL people with MS. This achievement gives me renewed optimism that the next generation of treatments—particularly for progressive MS—is just around the bend and that a world free of MS is not far behind.

This is a breakthrough with your name on it. It was made possible by your activism, your volunteering, your giving, fundraising and more. We made this happen through our collective and deliberate work—Together We Are Stronger.

Thank you for all you do to help change the world for people with MS! Here's to many more breakthroughs ahead.

Julie Kaufer  
President, Southern California & Nevada

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5150 W. Goldleaf Circle, Suite 400  
Los Angeles, CA 90056  
1-800-344-4867

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# FINDING SOLUTIONS FOR PROGRESSIVE MS

MIKE, DIAGNOSED IN 1983

Ocrelizumab (Ocrevus™, Genentech, a member of the Roche Group) was approved by the Food and Drug Administration (FDA) in March for use in primary progressive and relapsing forms of MS. **This is the first FDA-approved medication for primary progressive MS.** Read more at [nationalMSSociety.org/ocrevus](http://nationalMSSociety.org/ocrevus). You—as part of the MS movement—helped the Society fund early work that led to the development of this B-cell therapy. Thank you!

## Measuring treatment effect

The effect of treatment is more difficult to measure in progressive versus relapsing MS. Clinical trials involving people with relapsing MS often rely on counting relapses or doing MRI scans to detect immune activity. In progressive MS, there are few or no relapses, and

few or no recovery or remission periods when major symptoms improve. So progression is more difficult to measure and usually happens over long periods of time. This difference makes it hard to quickly detect whether a therapy is impacting progression and thus has made therapy development for progressive MS a challenge.

Ocrevus is the first success after many disappointments. Now there is progress from other clinical trials. For example, positive results were recently announced from a trial of BAF-312 (Siponimod) in secondary progressive MS, and there is new interest in wellness research to identify exercise, dietary and other approaches that will help people with MS live their best lives.

**YOU CAN HELP ADVANCE MS RESEARCH:**

- Join an event and fundraise, or give [nationalMSSociety.org/donate](http://nationalMSSociety.org/donate)
- Advocate for government support of medical research [nationalMSSociety.org/MSactivist](http://nationalMSSociety.org/MSactivist)
- Participate in research studies [nationalMSSociety.org/researchparticipation](http://nationalMSSociety.org/researchparticipation)

## What's next in progressive MS research?

Researchers are exploring what drives injury to the brain and spinal cord in progressive MS—to identify new potential therapeutic targets that may stop the damage along the injured pathways. Other focus areas include:

- Identifying factors that contribute to progression risk
- Finding a way to measure and predict the transition to progression
- Developing better animal models to inform the study of the mechanisms underlying MS and progression
- Testing approaches for preventing and treating MS progression, including repurposed FDA-approved therapies and strategies to repair nerve-insulating myelin and shield the nervous system from damage
- Exploring the potential of different types of stem cells and stem cell therapies such as HSCT for turning off immune attacks or stimulating repair; learn more at [nationalMSSociety.org/celltherapy](https://nationalMSSociety.org/celltherapy)

Over the past few decades, several medications that have FDA approval for diagnoses other than MS have been prescribed by doctors for the treatment of MS—also called “off-label” use. For each of these medications there is some, but often limited, clinical trial evidence of efficacy. Get the details at [nationalMSSociety.org/offlabel](https://nationalMSSociety.org/offlabel).

## More must be done to stop disease progression

We need to continue our investment in research to find solutions for progressive MS. We welcome the success of Ocrevus, and we remain focused on finding more and better solutions for treating all forms of progressive MS. ■

**The International Progressive MS Alliance** is a growing global initiative to end progressive MS. The Alliance brings together the world's leading experts in MS to identify the critical knowledge and treatment gaps where progress must be made to change the world for people with progressive MS. Read more at [progressiveMSalliance.org](https://progressiveMSalliance.org).



WHATEVER IT TAKES.

## WHAT IS A BREAKTHROUGH?

It's being able to button your shirt in the morning. It's walking to the supermarket, and all the way back home. It's getting back up on that bike, that surfboard, that horse. Feeling strong enough to fall in love. Continuing the job you were made for.

It's knowing that you and your loved ones will never worry about MS again—ever.

LEARN MORE AT [BREAKTHROUGHMS.ORG](https://breakthroughms.org)

# JUST THE TWO OF US

## BIKE MS® BRINGS A COUPLE CLOSER TOGETHER

After Joe Benassi had what he calls “the time of his life” riding in Bike MS, his wife, Josie, wanted to join him.

“I didn’t know what to say. I wasn’t sure she would be able to do that,” Joe says.

Josie has faced mobility challenges since being diagnosed with multiple sclerosis in 2009. Wanting to support his wife, Joe set out to find a solution.

“I found a used tandem bike on Craigslist,” he says. “It was life-changing



Joe and Josie, diagnosed in 2009, at Bike MS

for us. I’d come home from work, and Josie would be in her spandex ready to ride. It has changed her outlook on having MS. She’s gained better acceptance of the disease because she has a way of coping with it now.”

Together, Joe and Josie—who have been married for 19 years and have three children—have cycled more than 3,000 miles and raised \$33,000 (and counting) for the National MS Society.

“It’s brought us closer. We talk the whole time. It’s our time to connect,” Josie says.

To conquer the summer heat, Joe, an electrical manufacturing engineer, put his engineering knowledge to use and designed a cooling vest for Josie that circulates ice water through a tank on the back of the bike. With the help of a 3-D printer, he also created a custom cane-holder attachment for their bike so Josie can use her cane at rest stops.

**bike MS** *It's more than a ride*

Bike MS is an experience grounded in camaraderie and marked by passion, inspiration, determination and pure enjoyment.

People with MS who cycle in a Bike MS event can join the ‘I Ride with MS’ program and enjoy day-of-event benefits and a complimentary jersey from Primal Wear, the official apparel provider of Bike MS.



In November 2016, Josie experienced an MS flare-up that caused her to be hospitalized and threatened her ability to continue cycling. To keep her going, Joe found a tandem bike that could be custom built with individual pedaling that would allow Josie to rest if needed. Problem is, it also came with a \$6,000 price tag. That's when a good friend stepped in to help.

“He called me and said, ‘It’s done. I’m buying the bike. I signed up to ride [in

“Once I’m on the bike, I just go. I absolutely love it,” Josie says. “It has reinvigorated me. It has given me a sense of accomplishment.”

Bike MS], and I want Josie riding next to me,” Joe remembers.

This year, the couple’s 14-year-old son, Andrew, will also be riding alongside them. And the new tandem bike was completed in April—just in

time for Joe and Josie to begin training for Bike MS.

“I’m ready to go,” Josie says.

The couple says participating in Bike MS is one of the best decisions they have ever made.

“The bike allowed her to be proud,” says Joe. “Now she wears her ‘I Ride With MS’ jersey and she’s like, ‘Yeah, I have MS—and I’m going to be the best I can be.’” ■



Left: Josie’s custom cooling vest  
Right: the cane holder

**muck fest<sup>MS</sup>** **BUILT FOR LAUGHS**

MuckFest<sup>®</sup> MS is the **FUN** mud & obstacle 5K. No special training required!

We're also on a mission to end multiple sclerosis: 100% of your fundraising dollars benefit the National MS Society. Have a blast and make a difference!

**REGISTER AT MUCKFESTMS.COM**

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# NAVIGATING THE CHALLENGES OF MS

MS Navigators connect people to the information, resources and support needed to move their lives forward.

MS Navigators are highly skilled professionals who are supportive partners and help navigate the challenges of MS unique to each person's situation.

MS Navigators are trained to connect and provide:

- Information and education to help people with MS and their support teams powerfully advocate for what they need, when and how they need it
- Emotional support resources for people with MS as well as family and carepartners, including support groups and ways to connect with others living with MS
- Help to navigate the complexities of finding a healthcare provider, benefits, insurance and access to coverage, and employment
- Resources to face financial challenges and plan for the future
- Wellness strategies that can make an impact on quality of life with MS including diet, exercise, emotional well-being and connection to local wellness resources



- Assessment for personalized case management through the Edward M. Dowd Personal Advocate Program
- Crisis intervention in times of need ■

Call 1-800-344-4867 or visit [nationalMSSociety.org/navigator](http://nationalMSSociety.org/navigator) to connect to the information, resources and support you need to move your life forward—with the help of the MS Navigator® Program.

The National Multiple Sclerosis Society is proud to be a source of information on topics related to MS. The information provided is based on professional advice, published experience and expert opinion, but does not constitute medical or legal advice.





# ONLINE & IN-PERSON RESOURCES

Find your next opportunity to learn new skills—and polish up old ones—to live your best life with MS.

## LIVE FULLY, LIVE WELL

A Collaboration with Can Do MS®

Lifestyle behaviors and choices can impact both MS and quality of life. You can build hope, self-confidence and motivation to pursue your wellness goals—and develop your personal approach to living well with MS. Find a program near you at [nationalMSSociety.org/livefullylivewell](https://nationalMSSociety.org/livefullylivewell) or 1-800-344-4867.

## RESILIENCE: ADDRESSING THE CHALLENGES OF MS

Even if resilience—a mindset of growth and opportunities, of seeing obstacles as challenges rather than threats—isn't your natural tendency, you can learn strategies and practice them.

Move past coping and learn to **thrive**.

Find a program near you at [nationalMSSociety.org/resilience](https://nationalMSSociety.org/resilience) or call 1-800-344-4867.

## EVERYDAY MATTERS:

### LIVING YOUR BEST LIFE WITH MS

Increase your knowledge of positive psychology and develop a personalized plan for implementing these principles and achieving greater life satisfaction.

Find a program near you, or start now at [nationalMSSociety.org/everydaymatters](https://nationalMSSociety.org/everydaymatters) or 1-800-344-4867.

## WEBINAR & TELELEARNING SERIES

A Collaboration with Can Do MS

Held monthly on the second Tuesday, 8–9:15 p.m. ET:

- June 13: Accessibility
- July 11: Resilience / Coping Skills
- August 8: Advancing MS
- September 12: Navigating Healthcare

Register to join (online or by phone) at [nationalMSSociety.org/telelearning](https://nationalMSSociety.org/telelearning) or 1-800-344-4867.

# BIKE MS® AT THE PASADENA ROSE BOWL

After two years of riding from Santa Monica to Santa Barbara, Bike MS: Coastal Challenge moved to the historic Pasadena Rose Bowl in 2017.

“I wanted to do something to help make a difference and help others, but in the end I was more inspired by this great group of riders and volunteers,” said cyclist Susan Maldoon.

raising critical funds to create a world free of multiple sclerosis.

The ride began at Rose Bowl Stadium and traveled through the stunning San Gabriel Mountains, allowing cyclists to experience some of Los Angeles’ most iconic landmarks while



More than 700 cyclists chose 30-, 60- or 100-mile supported routes with fully-stocked rest stops every 10-12 miles and felt like champions as they crossed the Finish Line in the nation’s most famous college football stadium.

Cyclists celebrated the accomplishment with a Finish Line Party complete with music, beer garden and delicious food.

“The entire day was full of fun and inspiration that when people work together they can accomplish anything. Thank you for a memorable day I’ll never forget!”



**Save the date for 2018!**  
**Visit [bikeMS.org](http://bikeMS.org)**



# SUPPORT, CONNECTION & SELF-HELP GROUPS

**Antelope Valley**—3rd W, 6p  
Denis 951-764-1859

**Central LA**—4th Sat, 12p  
Brenda, 310-628-6771

**Downey, The Force**—Th, 10a  
Staci 213-343-9962

**Downey, Young Professionals**—  
2nd Sat, 10a. ypg@nmss.org

**Lakewood/Long Beach**—  
3rd Sun, 1p. Fran 562-925-4405

**Los Angeles**—3rd Th, 6p. Michael  
213-804-1249; Alison 323-876-7606

**LA: Veterans Administration**—Ken  
kenney357@me.com

**Monrovia/Pasadena**—2nd M, 10a  
Aynn 626-303-4343

**North Hollywood: Drumming**—  
2nd Sat, 12p. Beth 818-219-1715

**Santa Clarita**—2nd Th, 6:30p  
Eire 661-297-6887

**South Bay/Harbor City**—3rd Tu  
4:15p. Pattie 310-769-0694

**Tarzana/Northridge: Spanish  
Speaking**—2nd Sat, 9a  
Maria 818-370-8073

**Tarzana: Let's Play Social**—3rd Sat  
12p. Linda 818-222-7678

**West Covina**—2nd & 4th W, 11a  
Tadd 626-962-7909

**West LA: Men's Group**—  
3rd W, 6:30p. Larry 310-926-1641

**Channel Islands: Arroyo Grande**—  
2nd Tu, 6p. Ellen 805-343-6094

**Santa Barbara**—3rd F, 11:30a  
Michael 805-886-3000

**Santa Barbara**—2nd W, 6:30p  
Laura 805-637-5580

**Simi Valley**—1st M, 11a. Dennis 805-  
584-2526; Tina, 805-581-2264

**Thousand Oaks**—3rd W, 1p. Tina  
805-581-2264; Ken 818-518-4226

**MS Lunch Club**—Last F, 11:30a  
Donna 805-798-2201

**Ventura Social**—3rd Th, 3p  
Tammy 805-648-6402

## Inland Empire and Coachella Valley

**Apple Valley/Victorville**—1st Th  
10a. Katrina 951-906-1752

**Colton**—3rd Th, 9a  
tbrown@inlandcaregivers.org  
jlopez@inlandcaregivers.org

**Hemet**—1st W, 10a. Sarah 760-580-0658

**Ontario**—1st Sat, 10a. Emily 909-  
851-6204; Kathy 909-621-3519

**Palm Desert**—2nd Th, 1p  
Richard 760-899-4174

**Palm Springs**—2nd Sun, 12p  
Tony 760-831-6365

**Rancho Cucamonga: Moms with MS**  
—2nd Tu, 10a. awzmom@yahoo.com

**Riverside**—1st Sat, 10a Gilbert 951-  
544-1441

**Temecula**—1st M, 10a. Maby 760-562-  
4533; Jacqueline (Español) 951-302-3529

**Temecula: Men's Group**—Last M, every  
other month, 1p. Ric 619-985-5736

**Upland**—Last W, 10a  
Denise 909-519-4410

**Yucaipa**—3rd Tu, 1p. Clare 909-  
795-5128; Tom, 909-795-1717

## Nevada and Northeastern California

**Las Vegas/Henderson: Oasis Group**—  
2nd Th, 6:30p. Gina 702-604-6165

**Las Vegas: Young People with MS**—  
geoff.carlvin@gmail.com

**Las Vegas: MS Under 40**—Last W  
soteloc2@yahoo.com

**Las Vegas: MS Lunch Club**—1st Tu  
11:30a. Carol 702-633-4158

**Las Vegas: WestSide Stories**—3rd W  
6:30p. Gaby 702-328-6989

**Reno/Sparks**—2nd Th, 2:30p  
Chris 775-560-1215

**Reno/Sparks**—2nd Tu, 10a  
Mary 775-772-3404

**Reno: Caregiver Support**—2nd Th  
6p. Fred 513-703-3306

**Reno: Young People with MS Under 40**  
—3rd W, 5:30p. Dana 775-843-0784

**Truckee**—2nd Th, 5:30p  
Rick 530-550-0654

## San Joaquin Valley

**Bakersfield**—2nd & 4th W, 11a  
Ron 661-833-0388

**Bakersfield Spanish Speakers**—  
Alfredo 661-699-4171

**Clovis/Fresno**—3rd Sat, 9:30a  
Yolanda 559-908-4644

**Fresno: Newly Diagnosed/Working  
Professionals**—3rd W, 6p  
Myrna 559-349-0423  
Cherish 559-287-3042

**Fresno: Spanish Speaking**—  
Sharon 559-579-4096

**Hanford**—1st Sat, 10a  
Debra 559-585-8054

**Tehachapi**—2nd Th, 5p  
Linda 661-822-7440

**Tehachapi: Wheels in Motion**—  
3rd Tu, 10a. Linda 661-822-7440

**Visalia**—2nd Sat, 10a  
Mary Ann 559-936-3960

For an up-to-date list of groups and meetings visit [nationalMSsociety.org/CALSHG](http://nationalMSsociety.org/CALSHG), call 1-800-344-4867 or email [contactusNMSS@nmss.org](mailto:contactusNMSS@nmss.org).





## MS CONNECTION NEWSLETTER

900 South Broadway  
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Southern California & Nevada



**ONE DESTINATION:  
A WORLD FREE OF MS.**

**Bike MS: Vegas  
Saturday, October 28**

**REGISTER › [BIKEMS.ORG](http://BIKEMS.ORG)**

*Don't just ride, Bike MS*

THANK YOU TO OUR PREMIER NATIONAL SPONSORS **Bicycling** PRIMAL