MS Plane Pull
Sat, Jun 10 at Portland, Jetport, ME
nationalMSsociety.org/MAMcalendar

Join Bike MS®—bikeMS.org

• Ride the Rhode
  Jun 10-11, Newport, RI

• Cape Cod Getaway
  Jun 24-25, Quincy, MA

• Minuteman Ride
  Sat, Jul 15, Concord, MA

• Green Mountain Getaway
  Sat, Aug 5, Burlington, VT

• Great Maine Getaway
  Aug 12-13, Biddeford, ME

• New Hampshire Seacoast Escape
  Sat, Aug 26, Stratham, NH

Join Walk MS®—walkMS.org

• Sat, Jun 17: Lynnfield, MA

• Sat, Sep 16: Sturbridge, MA and Laconia, NH

• Sat, Sep 23: Keene, NH and Upper Valley (White River Junction, VT)

• Sun, Sep 24: Falmouth, MA

Living Well with MS Conference

• Sat, Jun 17, Auburn, ME**

• Sat, Jul 22, Concord, NH**

• Sat, Aug 19, Warwick, RI*

Register at nationalMSsociety.org/MAMcalendar or 1-800-344-4867

Kids Get MS Too Family Camp
Aug 11-13, Greenfield, NH
Register at nationalMSsociety.org MAMcalendar or 1-800-344-4867

MS Harborfest
Aug 18-20, Portland, ME
Register at nationalMSsociety.org/MAMcalendar

Resilience: Addressing the Challenges of MS
Mon, Aug 28, Methuen, MA
See page 8 for details. Register at nationalMSsociety.org/MAMcalendar

Live Fully, Live Well
Sat, Sep 2, Foxboro, MA
See page 8 for details. Register at nationalMSsociety.org/MAMcalendar

Challenge Walk MS®: Cape Cod
Sep 8-10, Brewster, MA
The Walk Will Challenge You. The Experience Will Change You. Register at challengewalkMS.org

Successful Tools to Conquer MS
Sat, Sep 16, Dorchester, MA
Register at nationalMSsociety.org MAMcalendar or 1-800-344-4867

*Everyday Matters. **Resilience
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 (more on page 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.

Lori A. Espino
President, Greater New England

101A First Ave.
Waltham, MA 02451

nationalMSsociety.org/MAM

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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
- Advocate for government support of medical research nationalMSsociety.org/MSactivist
- Participate in research studies nationalMSsociety.org/researchparticipation

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. 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!
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

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.

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.

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
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 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 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 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.’”
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 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.
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 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 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 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 or 1-800-344-4867.
MS IS MY OBSTACLE. I WON’T ALLOW IT TO BE MY EXCUSE.

In 2013, Carolyn Greene joined Climb to the Top Boston, a National MS Society fundraiser which involves climbing 61 flights of stairs to the top of 200 Clarendon Tower, New England’s tallest building. Sixty-one flights is a challenge for anyone; for Carolyn, who was diagnosed with MS in 2006 and uses arm crutches, it’s a true test of preparation and determination. “We each face unique obstacles in MS. I will continue to find ways to get beyond mine,” says Carolyn.

“Please know two things:
1. I have MS. It doesn’t have me.
2. MS is my obstacle. I won’t allow it to be my excuse.”

Carolyn founded and captains Team Extreme Greene Climbing Team which raises $2,000-3,500 annually. Friends and family—close and extended—travel from near and far to climb with and support Carolyn.

“People track me down and want to join the team. Some have been climbing with me all five years. And each year, some join the climb for their first time.

“If I can give just one person hope for a stronger tomorrow, or encouragement to find their way, then I have accomplished what I wanted! I do it for me, for MS, and for everyone who can’t complete the climb,” says Carolyn. “I will keep climbing for as long as I possibly can.”

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9 | MS CONNECTION Summer 2017 | Greater New England
### Support, Connection & Self-Help Groups

#### Maine
- **Bangor/Brewer:** Rachel rsprae@roadrunner.com
- **Caribou:** Debbie & Cliff 207-325-4019
- **Damariscotta:** Scott antlongscott@yahoo.com, megan.mccarthey@lchcare.org
- **Ellsworth:** Grace 207-930-9358
- **Madison:** Allie alliepoirier@gmail.com
- **Rockland:** Tom 207-354-0285
- **Sanford:** Bill 207-289-5886
- **Winslow:** Max 207-441-2589

**Coffee & Conversation**
- **Auburn:** last Tues, 10-11:30 a.m.
- **Chicopee:** Sharlene 413-330-3801
- **Dover:** 2nd Thurs, 5:30-7 p.m.
- **Exeter:** Bob 781-983-2093
- **Southbridge:** Michelle 508-949-6549, Jamie 774-230-2934
- **Southern Berkshire:** Lori 413-229-3621
- **Springfield:** Gayle 508-400-0869
- **Taunton:** Tracy 508-807-5181, Karen 508-863-4400
- **Waltham Core Connection Group:** Alan 617-599-3001
- **Waltham:** Marie 781-249-3633, Charlene 617-733-3303
- **Wareham:** Ashley 339-832-2763
- **Worcester:** Wayne 508-835-3993
- **Worcester, But You Look So Well:** Joan 774-261-3136, 508-869-6264

#### Massachusetts
- **Amherst Area:** Mary Beth 413-253-0894
- **Attleboro, Women with MS:** Polly 508-761-6380

**Coffee & Conversation**
- **Chicopee:** 2nd Wed 10-11 a.m.
- **North Adams:** 2nd Sun 3:30-4:45 p.m.

#### New Hampshire
- **Charlestown:** Tammy 603-826-3772
- **Concord:** Richard 603-783-4849
- **Derry:** Peg 603-668-6408
- **Dover:** Sandy 603-332-0652
- **Exeter:** Richard 781-844-4216, Lebanon/Upper Valley: Jill 857-891-2237, Susan 802-376-4801

**Coffee and Conversation**
- **Nashua:** 1st Tues, 10-11:30 a.m.
- **Manchester:** 2nd Tues, 6:30-8 p.m.
- **Concord:** 3rd Thurs, 6:30-8 p.m.

#### Rhode Island
- **Cranston:** marieperna@hotmail.com
- **Portsmouth:** Tom tw.ellis@cox.net
- **Wakefield:** Laure lauremanning@gmail.com
- **Warwick:** Sharon mspositiveperspectives@yahoo.com

**For an up-to-date list, visit nationalMSsociety.org/MAMSHG or call 1-800-344-4867**
ONE DESTINATION: A WORLD FREE OF MS.

Ride the Rhode, June 10-11
Cape Cod Getaway, June 24-25
Minuteman Ride, July 15
Green Mountain Getaway, August 5
Great Maine Getaway, August 12-13
New Hampshire Seacoast Escape, August 26