

2013 Bike MS: All Good Things Come in Threes!



Cyclists cruising at Bike MS: Hudson River Ramble.

All three Bike MS events in 2013 had perfect weather, enthusiastic and inspiring participants, and terrific volunteers. We collectively did a phenomenal job raising funds for research that will STOP MS in its tracks, RESTORE what's been lost, and END MS forever.

Bike MS: Finger Lakes Challenge

Amount Raised: \$127,777.80

Bike MS: Southtowns Shuffle

Amount Raised: \$31,448.41

Bike MS: Hudson River Ramble

Amount Raised: \$94,634.25

*all income totals as of 10/10/13

Bike MS is the premier fundraising cycling series in the nation. Funds from our Bike MS rides in the Upstate New York Chapter benefit more than 12,800 families across the state that are living with the challenges of multiple sclerosis. The National MS Society wishes to extend our gratitude to every supporter of Bike MS, and we hope you help us make the 2014 Bike MS series another phenomenal success!

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National Multiple Sclerosis Society

Upstate New York Chapter

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A Note From the Chapter President and CEO, Stephanie Kunes-Mincer

Well, 2013 proved to be a great year for Bike MS! With perfect weather for all three rides and successful fundraising from our dedicated cyclists, we raised more funds for our mission than we originally anticipated. Raising more dollars for research and programs is always a great accomplishment! The Great 8 cycling group that has raised over one million dollars for MS research rode through Upstate New York and around Lake Ontario this year, and the group decided to cross the finish line with cyclists at Bike MS: Southtowns Shuffle! Our two-day getaway ride, Bike MS: Finger Lakes Challenge, had 200 cyclists enjoying the beautiful scenic ride around Keuka Lake. Bike MS: Hudson River Ramble cyclists rode with fundraising totals “out of the park” to end our Bike MS season with a wonderful feeling of accomplishment.

My thanks to everyone who participated for all of your hard work and for raising the funds needed to help support those living with MS and to move us closer to a cure. I can’t wait to see you again this year at Bike MS!



A Note from Bike MS Manager, Alyssa Shoup

I am grateful, honored, and humbled to have had such a spectacular second Bike MS season with all of you. With what seemed like a slow start to the 2013 Bike MS season in terms of ridership and fundraising, we certainly ended with a BANG! We were blessed with absolutely perfect weather for all three of our Bike MS rides – that’s the one thing I cannot (yet) control, but I’m working on my perfect-weather-conjuring skills for you! The weather only enhanced the spirit and camaraderie that makes Bike MS so amazing – seeing everyone come together to accomplish personal goals and overcome challenges – all with a much larger vision and mission of finding a cure for MS. So thank you. Thank you for riding, volunteering, and supporting those affected by MS. I hope to see you at Bike MS 2014!

Financial Report

The National Multiple Sclerosis Society Upstate New York Chapter, Inc.
October 1, 2012 through September 30, 2013

Support, Revenue and Special Events

Special Events	\$1,945,462
Public Support	\$1,047,181
Other Revenue	\$120,244
Total	\$3,112,887

Expenses

Programs and Services	\$2,402,700
Fundraising	\$629,860
Management and General	\$105,075
Total	\$3,002,087
Total	\$3,137,635

Dollars You Raise Drive Research

MS Research Progress

MS research continued to advance on many fronts in 2012-2013. This year we saw:

- The approval of a second oral therapy for relapsing forms of MS and other emerging treatments progressing through the development pipeline;
- The launch of the International Progressive MS Collaborative, the largest effort to date to speed research to stop progressive forms of MS;
- The discovery of what could be a target of the immune attack in people with MS may lead to new understanding of the disease and new treatment strategies;
- Advances in uncovering MS triggering factors, bringing us closer to finding ways to prevent the disease; and many other advances pushing us closer to a world free of MS.

Progress Toward Stopping MS

The Society continued to invest in research to stop MS, including:

- Testing whether vitamin D, or the sex hormone estriol, or the probiotic approach of a sports drink containing parasite eggs, can reduce MS immune attacks;
- New projects focusing on discovering “biomarkers” for better diagnosis and treatments;
- Collaboration in a cross-disease drug screening initiative aimed at discovering the potential of compounds to stop nerve degeneration and protect the brain from harm;
- Providing funding for lab research to discover small molecules that can deliver therapies to areas of nervous system damage and protect against that damage in MS.

Progress Toward Restoring What's Been Lost

The Society supported new and ongoing initiatives to propel efforts to restore function to people with MS through discovery and Fast Forward research programs, including:

- New studies into the potential of adult skin cells and umbilical cord cells as a source of nervous system repair cells;
- Cutting-edge research to discover new targets to stimulate myelin repair and early testing of new approaches to treating MS symptoms;
- Advanced MRI analysis to determine how brain regions associated with pain are affected by MS.

Progress Toward Ending MS Forever

To drive efforts to understand what triggers MS and ways to prevent it, the National MS Society:

- Convened an international summit on vitamin D in MS;
- Renewed funding for an enhanced MS DNA core resource bank to foster better understanding of genes that make people susceptible to MS and may also control the course of an individual's MS.

The Society supported several new research projects aimed at:

- Understanding how risk factors such as vitamin D level and genes contribute to a person's susceptibility to developing MS;
- Investigating how bacteria that naturally live in the human body, including in the intestines, may influence MS susceptibility and disease activity.

Current Society-Funded Research Projects in Upstate New York:

Dr. Matthew Bellizzi, MD, PhD

Dr. Matthew Bellizzi, MD, PhD, at the University of Rochester, was awarded \$263,622 to research what contributes to the loss of nerve function in multiple sclerosis and to find ways to protect the nervous system from damage. This research could provide important information and techniques for developing treatments to limit nervous system damage in MS and its resulting progressive disability.

Dr. Fraser Sim

The National MS Society has awarded a three year, \$554,973 grant to Dr. Sim, to study the ability of an FDA-approved drug to improve myelin synthesis and repair in mice. Dr. Fraser Sim is an assistant professor of pharmacology and toxicology at the University of Buffalo School of Medicine and Biomedical Sciences. Employed at the University of Buffalo since 2009, his lab currently investigates the molecular control of cell fate and homeostasis of resident stem and progenitor cells in the human brain.

Dr. Steven Goldman, MD, PhD

Dr. Steven Goldman, MD, PhD, at the University of Rochester Medical Center, received a research grant of \$851,630 to use an innovative “humanized” model to manipulate and understand the behavior of human progenitors during the process of repeated myelin damage and myelin repair, similar to what occurs in MS. This could lead to better information on potential repair therapies for people with MS.

Dr. Murali Ramanathan, PhD

Dr. Murali Ramanathan, PhD, with The Research Foundation of SUNY Buffalo, received a \$704,784 research grant to study the role of cholesterol and related substances to guide diet and lifestyle choices that will improve disease outcomes in people with MS. The results may allow better management of MS as they could be used to guide therapies, diet, exercise, and other lifestyle choices to reduce MS disease progression.

Thank You to Our Sponsors



H.P. **Acthar**[®] GEL
(repository corticotropin injection) 80 U/mL



Mechanical Support:

Our mechanics help provide a smooth ride for cyclists both on the routes and at rest stops!

Bike MS: Finger Lakes Challenge

Full Moon Vista
Wheels Unlimited
Rochester Cycling & Fitness

Bike MS: Southtowns Shuffle

Bert's Bikes
Eastern Mountain Sports

Bike MS: Hudson River Ramble

Sports Authority
Downtube Bicycle Works

Volunteers Don't Just Do the Work, They Make it Work!



The Livonia United Methodist Church Group that supports Bike MS: Finger Lakes Challenge every year, and arguably have one of the best rest stops: cold wash cloths, homemade cookies, shoulder massages – they take good care of the cyclists!

Bike MS is a monstrous event that can only be tamed and managed with the commitment and hard work of volunteers across Upstate New York. More than 100 volunteers mapped out and marked the multiple routes for each event, established rest stop locations, secured sponsorships and donations, recruited and registered participants, delivered supplies along the routes, cheered on cyclists, and more. Imagine the impact of this volunteer force if each volunteer invited an additional friend or family member to Join the Movement® throughout the year. We're calling on volunteers who have made their mark against MS during Bike MS 2013 and want to do more, NOW.

Do you think you want to take an extra step as a volunteer with Bike MS next year? Do you have ideas and suggestions for Bike MS? Are you committed to raising awareness about how multiple sclerosis affects families in your community? We invite you to consider joining the planning team for Bike MS in your area. Planning teams are unique groups of volunteers who play a leadership role in promoting and implementing the event. Volunteers help spread the word, recruit teams and participants, and rally the support of businesses and organizations to help create a successful event.

A HUGE thank you to the 2013 Task Forces:

Bike MS: Finger Lakes Challenge:

Carolyn Argust
Coleridge Gill
Todd Hamann
Sandra Quiñones
Andrew Sorce
Paul Specter
Susan Touhsaent
Bob Touhsaent
Leslie Virgilio
Scott Wagner

Bike MS: Southtowns Shuffle:

Phil Geyer
Greg Harvey
Ron Stefanski

Bike MS: Hudson River Ramble:

Michael Halstead
Steve Marsh
Frank Ridzi
Randy Stein

Other volunteer opportunities with the Upstate New York Chapter:

- Volunteer teams for MS Service Day
- Office support volunteers in Buffalo, Rochester, and Albany
- MS Ambassadors
- Special event volunteers for other chapter events
- Corporate Development Task Force

Be sure to check out the volunteer section of our website for current information about opportunities: volunteerMSupstateny.org. You can also contact Ashley at ashley.greenman@nmss.org or 1-800-344-4867 (press 2) to get involved. Thank you to every volunteer who has committed to raising funds and awareness as part of the movement to create a world free of MS!

Bike MS 2013 Superstars

The Top 10 Teams and Top 30 Individuals are the crème de la crème of fundraising across all Bike MS events within our Chapter.

Top 10 Teams:

1. **Wheels for Warren** (formerly MS Miles for Mariann) – Team Captain Carolyn Argust – \$33,514 – Bike MS: Finger Lakes Challenge
2. **Team SOS Triathlon** – Team Captain Michael Halstead - \$19,397.20 – Bike MS: Hudson River Ramble
3. **Miles for Mom** – Team Captain Jessica Szatkowski - \$11,685.01 – Bike MS: Finger Lakes Challenge
4. **Aunt Jillian’s Carnival** – Team Captain Samantha Shipherd - \$11,112 – Bike MS: Hudson River Ramble
5. **Keuka MS Team 2013** – Team Captain Ken Buschner - \$10,916 – Bike MS: Finger Lakes Challenge
6. **Praxair – Western NY** – Team Captain Phil Geyer – \$9,990 – Bike MS: Southtowns Shuffle
7. **Vintage Raiders** – Team Captain James Andolina - \$6,635.01 – Bike MS: Finger Lakes Challenge
8. **Plummer’s Peddlers 88** – Team Captain Andrew Plummer - \$5,867 – Bike MS: Hudson River Ramble
9. **Jest Cycling** – Team Captain Barry Quinn - \$5,865.01 – Bike MS: Finger Lakes Challenge
10. **TEAM JESSICA** – Team Captain Jerry Assis - \$5,461.01 – Bike MS: Hudson River Ramble

Top 30 Individuals:

1. **Joan Flanagan** - \$10,085 – Bike MS: Hudson River Ramble
2. **Phil Geyer** - \$6,765 – Bike MS: Southtowns Shuffle
3. **Michael Schenker** - \$6,592.02 – Bike MS: Hudson River Ramble
4. **Ken Buschner** - \$5,670 – Bike MS: Finger Lakes Challenge
5. **Seth Ginsberg** - \$4,970 – Bike MS: Hudson River Ramble
6. **Carolyn Argust** - \$4,240 – Bike MS: Finger Lakes Challenge
7. **Michael Halstead** - \$4,025 – Bike MS: Hudson River Ramble
8. **Michael Asselta** - \$4,025 – Bike MS: Finger Lakes Challenge
9. **Todd Brown** - \$4,001.01 – Bike MS: Hudson River Ramble
10. **Sue Rangeley** - \$3,750 – Bike MS: Hudson River Ramble
11. **David Geiger** - \$3,706 – Bike MS: Hudson River Ramble
12. **JP Shipherd** - \$3,675 – Bike MS: Hudson River Ramble
13. **Steven Moses** - \$3,505 – Bike MS: Finger Lakes Challenge
14. **Mary Leigh Holub** - \$3,340 – Bike MS: Finger Lakes Challenge
15. **Kenneth Hinman** - \$3,110 – Bike MS: Finger Lakes Challenge
16. **Roger Zaenglein** - \$2,535 – Bike MS: Southtowns Shuffle
17. **Marcus Steck** - \$2,375 - Bike MS: Finger Lakes Challenge
18. **Helen Zamboni** - \$2,251 – Bike MS: Finger Lakes Challenge
19. **James Andolina** - \$2,165.01 – Bike MS: Finger Lakes Challenge
20. **Robert Chamberlain** - \$2,165 – Bike MS: Finger Lakes Challenge
21. **Joanne Schiffhauer** - \$2,070 – Bike MS: Southtowns Shuffle
22. **Philip Klingler** - \$2,040 – Bike MS: Finger Lakes Challenge
23. **Richard Kerbel** - \$2,000 – Bike MS: Finger Lakes Challenge
24. **Jerome Butterbrodt** – 1,880 – Bike MS: Hudson River Ramble
25. **Dick Rizzo** - \$1,860 – Bike MS: Finger Lakes Challenge
26. **Paul Specter** - \$1,795 – Bike MS: Finger Lakes Challenge
27. **Katherine Makris** - \$1,750 – Bike MS: Finger Lakes Challenge
28. **Tim Doyle** - \$1,730 – Bike MS: Finger Lakes Challenge
29. **Dominick Laboda** - \$1,615 – Bike MS: Hudson River Ramble
30. **Rebecca Szatkowski** - \$1,615 – Bike MS: Finger Lakes Challenge

Bike MS Traveling Team Trophy

Each year, the top fundraising team in the chapter is awarded a “traveling trophy” to display, and the team name is etched into the base of the trophy. For the ninth year in a row, Carolyn Argust’s team, Wheels for Warren (formerly MS Miles for Mariann), is the top fundraising team. Congratulations to Wheels for Warren for raising a jaw-dropping \$33,232 this year!



SPOKENotes Spotlight:

You stand tall, rally your friends and family, inspire others to give, and deeply believe in the cause. We appreciate all that you do to make Bike MS extraordinary. Here are just a few highlights of participant successes across the chapter.

Michael Halstead:

Last year Michael Halstead registered at the last minute, after being diagnosed with MS and raised several thousand dollars. This year, he joined the Hudson River Ramble task force, playing an integral role in the implementation of the stellar ride experience, and he captained a team of 37 new participants who raised more than \$19,500 this year!

Robert Chamberlain:

Riding for a friend and colleague, Bob created Team Karen, accepted the challenge and conquered his first ever century ride at Bike MS: Finger Lakes Challenge! He also raised \$2,165 in his first year – earning himself a spot in the Top 30 Individual Fundraisers club!

Team Bruised Tailbones:

Captain Kevin Rockmann and team members Tom Ward and Gregory Northcraft of Team Bruised Tailbones have made it their mission to ride in a Bike MS event in every state in the nation! This year, Finger Lakes Challenge was Tom's 22nd state and Kevin's 14th state. They are extraordinary, riding in two Bike MS events per year, and they are consistently top fundraisers. This year they collectively raised \$1,729.

Joanne Schiffhauer:

Joanne Schiffhauer, captain of new Bike MS: Southtowns Shuffle team Refuse to Lose, took the bull by the horns and charged head on into 2013. She captained a team of six cyclists who collectively raised \$5,030, and she herself landed in the Top 30 Individual Fundraisers club! Joanne also captains the Walk MS team of the same name – for which she and her team raised nearly \$2,000! Joanne is truly a champion of the movement!



Team Praxair heading out for Bike MS: Southtowns Shuffle!



One of our outstanding volunteers pausing for a moment to enjoy the view of downtown Buffalo from Chestnut Ridge Park – the start/finish location for Bike MS: Southtowns Shuffle.



Cyclists leaving one of our stellar rest stops at Bike MS: Southtowns Shuffle.



Cyclists taking off at Bike MS: Finger Lakes Challenge!



**National
Multiple Sclerosis
Society
Upstate New York
Chapter**

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DOUBLE UP your participation with Bike MS! We have an exciting new program to participate in TWO Bike MS events within our chapter! Check out bikeMSupstateny.org for more info!

Register Today for Bike MS: 2014

Event

Bike MS: Finger Lakes Challenge

Bike MS: Southtowns Shuffle

NEW! Bike MS: ROC the Ride

Bike MS: Hudson River Ramble

Date

July 19-20

August 9

September 7

September 20

Location

Keuka College, Keuka Park

Sahlen's Sports Park, Elma

Genesee Valley Park, Rochester

Birch Hill Catering, Schodack

If you're a Team Captain looking to grow your teams, we have an exciting opportunity to tell you about!

Call Alyssa for details!
1-800-344-4867 (press 2)

