

MUSCLES MATTER

MDA
MASSACHUSETTS



May 2014



Come to MDA Summer Camp!



It's not uncommon for youngsters with neuromuscular diseases to feel isolated, as if no one understands their physical and emotional struggles. Participation in physical activities is often limited because of the special adaptations required. Each year, local children, ages 6-17, attend a free weeklong accessible summer camp where they get to be "just kids," in a supportive environment with other kids who have similar disabilities. Activities are geared to campers' abilities, and each camper is assigned a trained, full-time volunteer assistant.

This weeklong summer camp is also an opportunity for parents to get a welcomed break from their role as full-time caregivers and they are refreshed and ready to resume their responsibilities after camp.

MUSCULAR DYSTROPHY ASSOCIATION

508-898-3375

worcester@mdausa.org

33 Lyman Street, Suite 205, Westborough, MA 01581

MDA Summer Camp Counselors 18+ Needed

Camp Allen, Channel 3 Kids Camp, Camp Waban

Want to get more out of your summer? Volunteer your time to give a kid with muscular dystrophy the best week of their year. From swimming, fishing tournaments, power soccer to arts and crafts, these campers get to experience a barrier-free week thanks to the help of people like you. You must be 18+ to be a camp counselor.

This week-long, overnight camp is available for children ages 6-17 who are living with neuromuscular disease. Call the MDA for more information about how you can volunteer!

508-898-3375

Responsibilities of a volunteer counselor:

-  Assisting with fun camp activities such as games, crafts, swimming, fishing, scavenger hunts, camp fires, talent shows and more.
-  Daily living assistance including bathing, dressing, brushing teeth and toileting.
-  Ability to work in a team led by a unit leader to ensure all campers are cared for.
-  Volunteers must be at least 18 years of age, a United States Citizen, and go through the application process including interview, medical, physical and criminal background check.

May is ALS Awareness Month!

The Blue Cornflower is the international flower of hope for ALS

It is a very courageous plant, being able to stand up to all the elements of nature.

It was chosen to symbolize ALS, as it is hardy despite its fragile appearance.



MDA
ALS DIVISION

Massachusetts MDA Staff:

David Spellman, *Director of Health Care Services*

Vanessa Malfitano, *Area Director - Boston North*

Kate Tighe, *Area Director - Boston*

Molly McDermott, *Health Care Coordinator*

Brittany DeFrancesco, *Fundraising Coordinator*

Brad Gosselin, *Fundraising Coordinator*

Will Southall, *Fundraising Coordinator*

Lindsay Johnson, *Endurance Manager*

Amy L'Heureux, *Administrative Assistant*

Lucia Doucette, *Health Care Administrative Assistant*

Katie Macomber, *Administrative Assistant*

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Upcoming Events

May 21

Cape Ann Lock-up
Lobsta Land
Gloucester, MA

www.mdalockup.org/capeannlockup

May 29

MDA ALS Evening of Hope
Doubletree Hotel
Westborough, MA

www.mdaevingofhope.com

June 6 –7

24 Hour Muscle Walk Challenge
Ipswich High School
Ipswich, MA

www.musclewalkmda.org/24hourwalk

June 9

Tavern in the Square MDA Cure Classic
Bass Rocks Golf Club
Gloucester, MA

www.TavernMDACureClassic.com

June 16 & 17

Bruce McCorry Kick-A-Thon
Burce McCorry Martial Arts
Peabody, MA

www.mdaevent.org/brucemccorykicks

June 19

Order of the Eastern Star
Walk for a Cure
Lake Quannapowitt
Wakefield, MA

June 25

Springfield Lock-Up
Samuel's
In the Basketball Hall of Fame
Springfield, MA

July 6-11

Summer Camp
Camp Allen
Bedford, NH

July 12-18

Summer Camp
Camp Waban
Sanford, ME

July 27 - August 1

Summer Camp
Channel 3 Camp
Andover, CT

October 19

Halloween Witch Ride
Boston Harley-Davidson
Everett, MA
www.mdawitchride.com



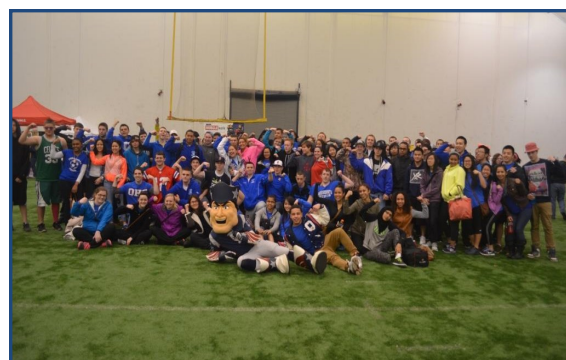
Thank You!

We can't believe how great everyone did at the Muscle Walk! This was an amazing year, thank you for making the 2014 Muscle Walk a truly wonderful experience. Please accept our sincerest, most heartfelt gratitude. You made a difference. We all made a difference together.

So what's next? The Muscular Dystrophy Association wants to hear from you. What did you think about your Muscle Walk experience? From registering, to fundraising, to event day, we want to know what you think. With your feedback, we will work to improve the Muscle Walk each year and make sure to keep the things you loved and get rid of the things you don't love.

We will post our FINAL number VERY soon but until then don't forget it's not too late to fundraise! Our Walk page will be open to donations for another MONTH so you can keep going! It's not too late to double your donations — ask ALL your donors to check with their employers to see if they'll match a gift to the Muscular Dystrophy Association. This will be your last chance to double your donations. Find out how you can double your donations at:

MDA.ORG/WAYS-TO-HELP/MATCHING-GIFTS



Thank You Again to our 2014 Sponsors!!



Nothing is **STRONGER** than **HOPE**

Muscle Walk Featured Sponsor MV-1!

“Convenience Provides Freedom”

When asked to write an article about the MV-1, we decided to ask, “How does the MV-1 work for your family?” The Barnes family and the Moy family both took on the challenge. After talking with them, we believe it can best be summed up by saying *“Convenience Provides Freedom”*.

Justin Moy tells us that the motorized ramp provides a wide wheelchair ingress path and provides his caregivers ease of access. Justin’s grandparents use the vehicle to transport him to his many activities. And, his 5-year old sister, Veronica, loves to help deploy the simple ramp system for her older teenage brother.

Proud to Support The MDA Muscle Walk



*According to Justin’s dad,
Christopher, “the design of the
MV-1 is clean and efficient.”*

Christopher Moy told us that his family looked at many other wheelchair accessible vans before choosing the MV-1. “For our family”, according to Christopher, “the MV-1 removes those reasons that made it so difficult to go out with our family in the past. When you have a person that requires the use of a wheelchair, you always have to plan ahead. The MV-1 gives us one less thing to plan: Transportation. The convenience of the MV-1 provides our family freedom.”

MV-1

of MASSACHUSETTS

A Herb Chambers Company



According to Rachel Barnes, “We needed our first accessible vehicle just as the MV-1 was rolling off the assembly line for the first time. It was a natural fit for our busy family. Who doesn’t want total accessibility without the hassle of customization and the additional costs associated with that? This vehicle works for everyone in our family, transporting a power chair as well as a pile of fall leaves, and it turns heads, too! We’ve driven ours proudly for two years, and look forward to using it for many more.”

MV-1 of Massachusetts
93 Cambridge St. Burlington, MA 01803
781-265-4444

www.HerbChambersMV-1.com

Email: LCantwell@HerbChambers.com

Facebook: [HerbChambersMV-1](https://www.facebook.com/HerbChambersMV-1)

Twitter: [MV1_MA](https://twitter.com/MV1_MA)

So, what is an MV-1? Mobility Ventures LLC says it best: “The MV-1 is the only purpose-built vehicle designed from the ground up to accommodate wheelchair accessibility. It already meets or exceeds the guidelines of the Americans with Disabilities Act (ADA) from the moment it rolls off the assembly line.” And, in our opinion, it proudly displays its “Made in the USA” logo! The MV-1 is assembled by AM General LLC in the world-class assembly facility in Mishawaka, Indiana.

Featured Muscle Walk Sponsor Amramp!

When someone is experiencing mobility challenges, their home can turn from a warm and nurturing environment into a very scary and dangerous place.

People who use a wheelchair or struggle with stairs often find it difficult to get in and out of their home and are subject to slip and fall accidents. Now that spring seems to have finally arrived, everyone wants to get out and enjoy the nicer weather, but some are nervous about negotiating their own front steps. A simple wheelchair ramp can make it easier to enter and exit the home and limit accidents.

People want to stay in the safety and security of their homes surrounded by the people they love.

MDA families can trust the Amramp Team to provide safe access in, out and around the house to maintain independence and quality of life.

We are a nationwide company with 40+ independently owned and operated locations across the USA and parts of Canada. Each location has a well stocked inventory of wheelchair ramps and other accessibility equipment which allows us to install the right solutions in a matter of days.

Our accessibility experts will personally visit the families at home and provide a FREE evaluation of their accessibility needs in accordance with the guidelines of the Americans with Disabilities Act. Our products are also available for rent – great for travel, apartments or short term disabilities.

Our modular wheelchair ramps are designed with safety in mind, with a unique open mesh, non-skid surface to allow moisture to pass through, minimizing dangerous ice film or mold build-up. Unlike wood or aluminum ramps, our steel ramps are fireproof, allowing for a safe exit in case of emergency.

Our ramps maintain property values. They are free standing. No digging, excavation or building permits required. When the ramp is no longer needed, it can be removed, moved and re-used, leaving no permanent damage to the home or the property.

Amramp now proudly offers an expanded line of accessibility equipment, including stair lifts, overhead patient lifts, portable wheel-in showers, vertical platform lifts, threshold and entry ramps, portable ramps, pool lifts, and more.

Amramp, North America's leading wheelchair ramp company, is a proud supporter of the Muscular Dystrophy Association and the ALS Association across the country. We sponsor a variety of MDA and ALS events and provide products and services for individuals with muscular dystrophy and ALS and you may have seen our ads in *Quest Magazine*.

Amramp

www.amramp.com

800-715-7598





Honey Farms #85



Nouria - check presentation



Lowes - Woburn

MDA's ALS *Evening of Hope*

Thursday ~ May 29th, 2014

Doubletree Hotel by Hilton
Westborough, MA

MORTON H. SIGEL MEMORIAL AWARD

PRESENTED TO: ERA Key Realty Services

JAMES E. WALLACE JR., EVENING OF HOPE SPIRIT AWARD

PRESENTED TO: Matthew R. Bruce (In memorium)

MDA LOU GEHRIG HUMANITARIAN AWARD

PRESENTED TO: Merit Cudkowitz, MD

For more information, please contact our office at 508-898-3375 or visit www.mdaevingofhope.com

Research Updates

Stay connected to MDA's worldwide research team, and get the latest research news online at www.mda.org/research!

MDA Thrilled That FDA Will Consider Accelerated Approval for New Muscle Disease Drug Aimed at DMD

Background:

Sarepta Therapeutics of Cambridge, Mass., has received word from the U.S. Food and Drug Administration (FDA) that the agency will consider an [accelerated approval pathway](#) for eteplirsen, an experimental drug the company is developing for boys and young men with [Duchenne muscular dystrophy \(DMD\)](#) who can potentially be treated by skipping of exon 51 of the dystrophin gene.

MDA has provided support for the development of [exon skipping](#), a gene modification strategy for treating DMD and potentially other muscle diseases, since the 1990s. It has funded foundational research that has made drugs like eteplirsen possible.

The application for approval of eteplirsen to treat DMD will be filed by Sarepta under an FDA program that allows a promising drug for a serious disease to be approved on the basis of evidence that the drug is "reasonably likely to predict clinical benefit," rather than providing evidence of actual clinical benefit, such as lengthened life span or clearly improved function.

The FDA requires that at least one additional, confirmatory study be conducted when a drug is approved in this accelerated manner, but patients can have access to the drug while that confirmatory study is being conducted.

Sarepta says it plans to begin an open-label, large-scale, confirmatory study of eteplirsen in DMD patients who can walk and have dystrophin gene mutations near exon 51 during the third quarter of this year. Trial sites in the U.S. and Canada are anticipated, and a historical control group, instead of a placebo group, will be used to measure drug effects. All trial participants will receive eteplirsen.

...

Statement:

"We're thrilled that the FDA has decided to allow an accelerated approval pathway for eteplirsen," said Valerie Cwik, M.D., MDA's chief medical and scientific officer. "Given MDA's mission to save and improve the lives of anyone fighting muscle disease, safe and effective drug development remains a critical priority as we work earnestly to find treatments and cures on behalf of the families we serve. We're especially pleased to see a clear path forward for this promising exon-skipping drug."

Thanks to our supporters, MDA has had a rich and unparalleled role in funding the foundational research that has made the progress we're seeing today possible. Our goal now is to finish the fight by moving from clinical trials into widespread drug deployment, and today's development is an important mile marker in that journey."

Families can stay informed by going to the [MDA website](#), the [Sarepta website](#), and [ClinicalTrials.gov](#), where details will be posted as they become available.



[SMA: Olesoxime Results Look Promising](#)

Preliminary results for a phase 2 trial of the experimental compound olesoxime suggest it may preserve motor function in spinal muscular atrophy... [More](#)



[MTM Natural History Study Seeks Participants](#)

A study to determine the usual disease course of myotubular myopathy has sites in North America and France... [More](#)



[DMD: Phase 2 Drisapersen Results Encouraging](#)

A phase 2 trial of Duchenne MD drug drisapersen found the high-dose group walked farther than the placebo group at 24 and 48 weeks...



MDA TEAM MOMENTUM – JOIN US FOR OUR INAUGURAL YEAR!

The Muscular Dystrophy Association's Team Momentum is the MDA's newest fundraising initiative that gives participants the opportunity to dedicate their participation in an endurance race – a marathon or half-marathon – to the fight against muscle disease! MDA Team Momentum participants are provided world-class training, mentors, a solid community of support, and inspiration every step of the way! Our program is open to all levels and abilities, whether a seasoned athlete, or a beginner who wants to make a difference! Please visit www.MDATeam.org to learn more and sign up!

2014 Opportunities

MDA Team Momentum is proud to be a charity partner of the **Michelob Ultra Boston 13.1** half marathon on September 14th, the **Bank of America Chicago Marathon** on October 12th, and the **Marine Corps Marathon** in Washington D.C. on October 26th! Participants can receive a race entry through Team Momentum for these races, and team training will begin in June in Boston or virtually!



How to sign up

If you would like to sign up as a participant, please visit MDATeam.org to review the details and sign up for our team! We are also hosting Information Socials to learn more about the team and get to know other participants! Please visit our [Learn More](#) page to see the full list of upcoming socials and to RSVP!

Volunteers Needed!

We are putting together an MDA Team Momentum Volunteer Committee to support Team Momentum! Volunteer opportunities include community outreach, grassroots marketing, event planning, program development, and participant experience planning! Whether you are available for a single event or would like to get involved on the Committee we can use your support!

UPCOMING INFORMATION SOCIALS!

May 7, 2014 (Wednesday), 6:30PM

Tavern on the Square Central Square Location -
730 Massachusetts Avenue, Cambridge, MA 02139-3335

May 10, 2014, (Saturday), 9:00AM

Athleta- Natick Mall - 1245 Worcester Street, Suite 1168
Natick, MA 01760.

May 13, 2014 (Tuesday), 6:00PM

Dillons - 955 Boylston St, Boston, MA 02115.

Information Social and Happy Hour.

May 15, 2014 (Thursday), 6:00PM

Boston Public Library (Copley Square)- Johnson Conference Room 2
700 Boylston St, Boston MA 02116

May 17, 2014 (Saturday), 9:00AM

Brookline Marathon Sports - 1638 Beacon Street,
Brookline, MA 02445.

May 22, 2014 (Thursday), 6:30PM

Watertown Free Public Library- Mastrangelo Room (2nd floor)
123 Main Street, Watertown, MA 02472

TM KICK-OFF: June 5, 2014 (Thursday), 6:00 pm

Social Restaurant and Bar @ the Crowne Plaza
320 Washington Street, Newton, MA 02458.

Please contact Lindsay at

508-621-7895 or LJohnson@mdausa.org

if you would like to Volunteer, learn more, or if you have any questions! To sign up please visit MDATeam.org!

Support the Muscular Dystrophy Association
and enjoy a great day of golf at the



Monday, June 9th, 2014

The day will begin with golf in the morning and a lunch reception to immediately follow at Tavern in the Square in Salem, MA with great food, cocktails, raffles, and much more!

Bass Rocks Golf Club
Gloucester, MA



www.TAVERNMDACURECLASSIC.com

24 HOUR MUSCLE WALK CHALLENGE



JUNE 6-7

@Ipswich High School's
Ken Spellman Track

JOIN US IN THE FIGHT AGAINST
MUSCLE DISEASE AND
REGISTER TODAY!



www.MuscleWalkMDA.org/24HourWalk

HOP-A-THON[®]

MDA's disability awareness program

Building Awareness, Teaching Acceptance,
and Motivating our Children to Help Others, thanks
to our schools that are out there Hoppin'!

The Hop-A-Thon program gives us the opportunity to
educate children on the needs of the people we serve and
the services we provide as well as motivate them to work
together to make a difference by supporting MDA.

If you would like to participate or hear more about
the program please contact Brittany at

(508) 898-3375

or email at bdefrancesco@mdausa.org



Watch for upcoming Fill The Boot drives.

Check us out on Twitter and Facebook
for more information!!



[Facebook.com/MDA.Massachusetts](https://www.facebook.com/MDA.Massachusetts)

MDA[®]
MASSACHUSETTS

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