Why MDA Matters

For kids with muscular dystrophy, ALS and related diseases, the freedom to walk, talk, run and play, laugh, hug, eat and breathe are taken away.

These devastating diseases severely weaken muscle strength and mobility. They take lives. **Currently there are no cures.**
MDA: A Movement More than 1.5M Strong

- 100,000+ Kids and adults registered with MDA
- 12,000 Registered volunteers
- 10,000 MDA advocates supporting public policy initiatives
- 300,000+ unique monthly visitors to mda.org
- 1 million Combined readers of Quest magazine & MDA Strongly blog
- 87 MDA Field Offices

- 35,000+ Attendees to nearly 500 golf events & galas
- 100,000+ Volunteers at Fill-the-Boot events
- 31,000 Retail locations participating in MDA events
- 10,000+ emails and calls answered by MDA’s National Resources Center annually
- 3,800 kids attending Summer Camp at no cost to their families
- 50,000+ Muscle walk participants on 5,200 teams each year

> 1.5 million
MDA connects the neuromuscular community

Funding research breakthroughs across diseases.

Caring for kids and adults from day one of diagnosis.

Empowering families with services and support.
A Lifetime Investment

- MDA is committed to providing the “best week of the year” to more kids than ever before — our goal is to send a total of 20,000 kids to camp by the year 2020.
- MDA invests $2,000 per year, per child, so campers and families can experience camp at no cost.
  - This investment to send kids to MDA Summer Camp includes all associated expenses that make a safe, healthy and enriching camp experience possible.
- MDA Summer Camp provides kids with opportunities to discover new interests, gain self-confidence and learn valuable life skills that prepare them to advocate for their needs, become independent and live unlimited.
Progress for Duchenne Muscular Dystrophy

**Life expectancy:** Increased from 16 years old to 25 years old

- **1950s:** Learning about muscles and nerves
- **1960s:** Advances in medical care
- **1970s:** DMD gene found
- **1980s:** Dystrophin identified
- **1990s:** MDA funds exon skipping research
- **2000s:** Launch of clinical trials for new drugs (many MDA supported)
- **2010s:** Exondys 51 receives accelerated approval from the FDA in 2016
- **2010s:** Deflazacort under FDA review in 2017

**Life expectancy:**

- **1950s:** 16 years old
- **2010s:** 25 years old

*Note: MDA = Muscular Dystrophy Association*
The Fight to End ALS: A Hopeful Frontier

“Because of MDA we have hope for ALS patients today. Because of MDA we’re making advances in understanding the genetic forms of ALS; moving therapies ahead; developing biomarkers for ALS — all of the tools necessary to change the course of tomorrow’s patient because of MDA.” – Jeffrey Rothstein, M.D., Ph.D. Johns Hopkins University

MDA currently has 33 active ALS research grants with a total funding commitment of $8.8 million.

Radicava first ALS treatment in over 20 years approved 2016
Progress for Spinal Muscular Atrophy (SMA)

The pace of therapy development in SMA is unprecedented, given that the causative gene was only discovered in 1995.

- Discovery of SMA causative gene (SMN)
- First drug studies in mice for SMA
- First studies testing antisense therapy in SMA mice
- First clinical trial testing antisense therapy for SMA
- First clinical trial testing gene therapy for SMA
- First clinical trial testing gene therapy for SMA

First drug for SMA (Spinraza) approved in December 2016

It's a hopeful time for SMA patients and families, as promising therapies are moving closer to approval.

SMA Added to National List of Disorders to Screen for at Birth in 2018
MDA Philadelphia

Local Families
➢ We serve 2,000 families in the Greater Philadelphia Area which includes South Jersey and New Castle County, DE

Local MDA Summer Camp
➢ We give 50+ kids the BEST WEEK EVER at MDA Summer Camp
➢ Variety Club Camp, 2950 Potshop Rd, Worcester, PA 19490

Care Center
➢ We have 5 Care Centers in our district that saves 12 doctor visits for our families a year
   ➢ MDA/ALS Center of Hope at Temple University Hospital
   ➢ Hospital of the University of Pennsylvania
   ➢ ALS Center at Pennsylvania Hospital
   ➢ Nemours/A.I.duPont Hospital for Children
   ➢ Children’s Hospital of Philadelphia

Local Support Groups
➢ Young Adult Group
➢ Individuals with ALS and their families
➢ MDA Resource Support Group

Research Projects in Philadelphia
➢ Tejivir Khurana, University of Pennsylvania, DMD, $240,000 over 3 years, awarded in 2017
➢ Angelo C. Lepore, Ph.D., Thomas Jefferson University, ALS, $300,000 over 3 years, awarded in 2015
➢ Diane E. Merry, Ph.D., Thomas Jefferson University, spinal-bulbar muscular atrophy (SBMA), $300,000 over 3 years, awarded in 2015
➢ David Trotti, Ph.D., Thomas Jefferson University, ALS, $300,000 over 3 years, awarded in 2015

Some other benefits at no cost to our families
➢ Educational Seminars
➢ Equipment Assistance
➢ Resource Center
➢ Young Adult Program
➢ Quest Magazine
➢ Mda.org
➢ Advocacy
Local Families

➢ MDA in Maywood serves 11 counties from South to North Jersey and 2 counties in New York, providing support and services to nearly 1900 local kids and adults.

Local MDA Summer Camp

➢ Our Summer Camp located in Hardwick, NJ brings over 60 local kids to two separate weeks of barrier-free fun with their friends. Our locals make sure it is the best week ever for our campers as they assist with boating at camp each year.

Local Care Centers

➢ Our MDA Care Centers are located at Rutgers Newark and Robert Wood Johnson New Brunswick.

Local Support Groups

➢ Young Adult Group
➢ Individuals with ALS and their families
➢ MDA Resource Support Group

Local Activities

➢ We have several family events throughout the year that locals have participated in, including a family picnic, fall festival, and our annual Muscle Walk.
South New Jersey Locals

Atlantic City Int'l Airport S0018
Bridgeton Local 4822
Brigantine L2657
Burlington County L3091
Camden City L0788
Camden County L3249
Cape May L3495
Cherry Hill L2663
Deptford L3592
Evesham L4687

Gloucester L4687
Mount Laurel L4408
Northfield L2364
Ocean City L4032
Pleasantville L2616
Robbinsville L3786
Salem L4154
Washington Township L4204 & L4320
West Windsor L3610

MDA Philadelphia works with 8 out of the 19 Locals in South Jersey. We would like to work and have relationships with all 19 in some capacity.
North New Jersey Locals

Our Fire program raises over $60,000 annually from boot drives, to bowling tournaments and everything in between. Locals who are unable to Fill on the streets have found success with bowling tournaments, golf outings or filling outside of a local grocery store. If a department is struggling with where to begin feel free to reach out to Ashley or Erin in NJ office at atharp@mdausa.org, edresnick@mdausa.org or 201-843-4452 - we’d love to pop in on a district or union meeting and meet everyone!
Fundraising Ideas

• Fill the Boot
  • On the street
  • At an event
• Digital Fill the Boot Drive
  • Add to existing drives or use easy website fundraising tool
  • https://filltheboot.donordrive.com/
• Beerfest
• Bowling Event
• Chili Cook-Off
• Competitions
• Golf Tournaments
Stay Connected

Facebook
@MDAPhiladelphia
@MaywoodMDA

Twitter
@PhiladelphiaMDA
@MaywoodMDA

Instagram
@MDAPhiladelphia
@maywoodmda

www.mda.org
Thank You!

MDA

AFL-CIO CLC