



MDA<sup>®</sup>



# 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



**1million**  
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**



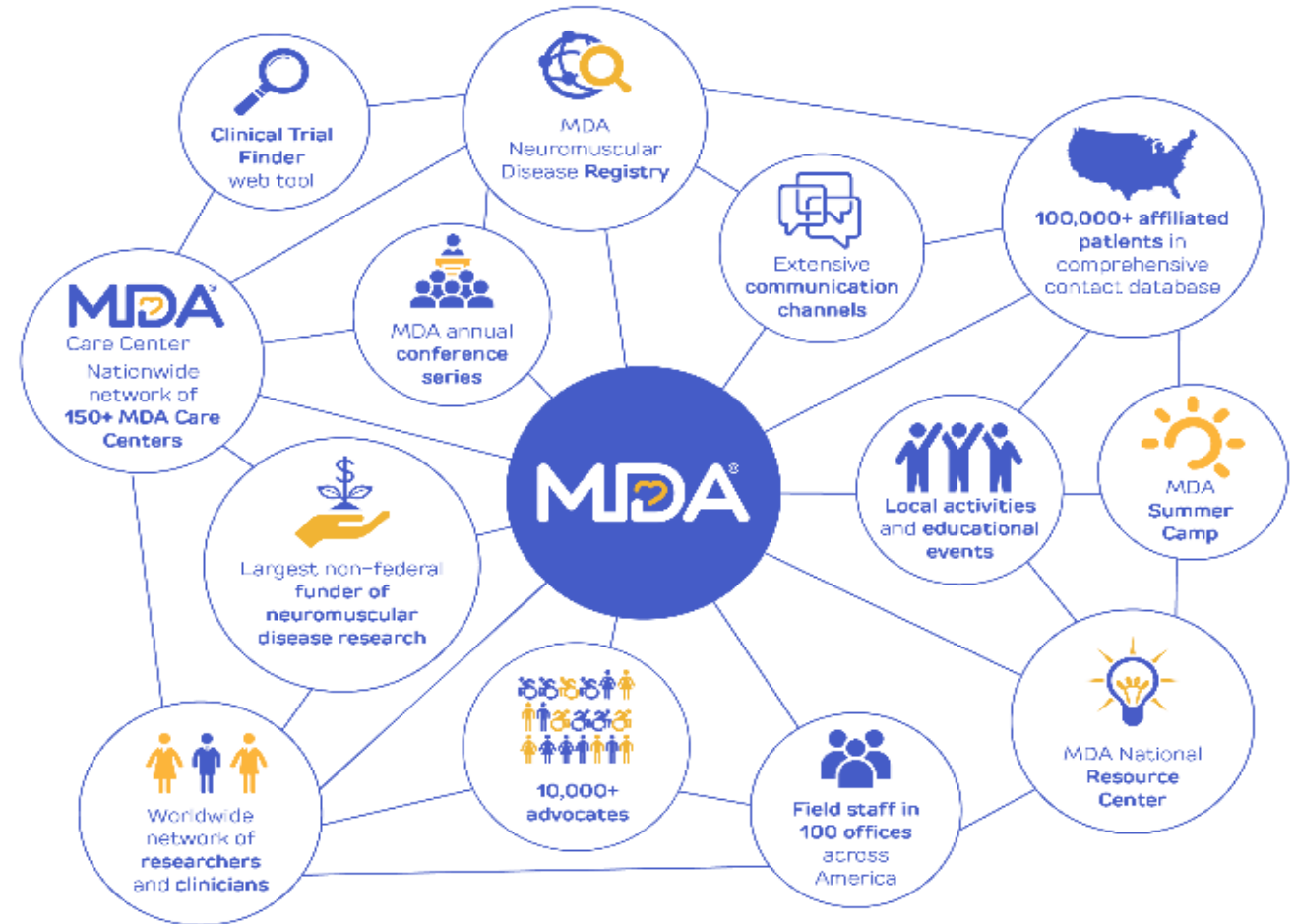
# MDA connects the neuromuscular community



Funding research breakthroughs across diseases.

Caring for kids and adults from day one of diagnosis.

Empowering families with services and support.



# A Lifetime Investment



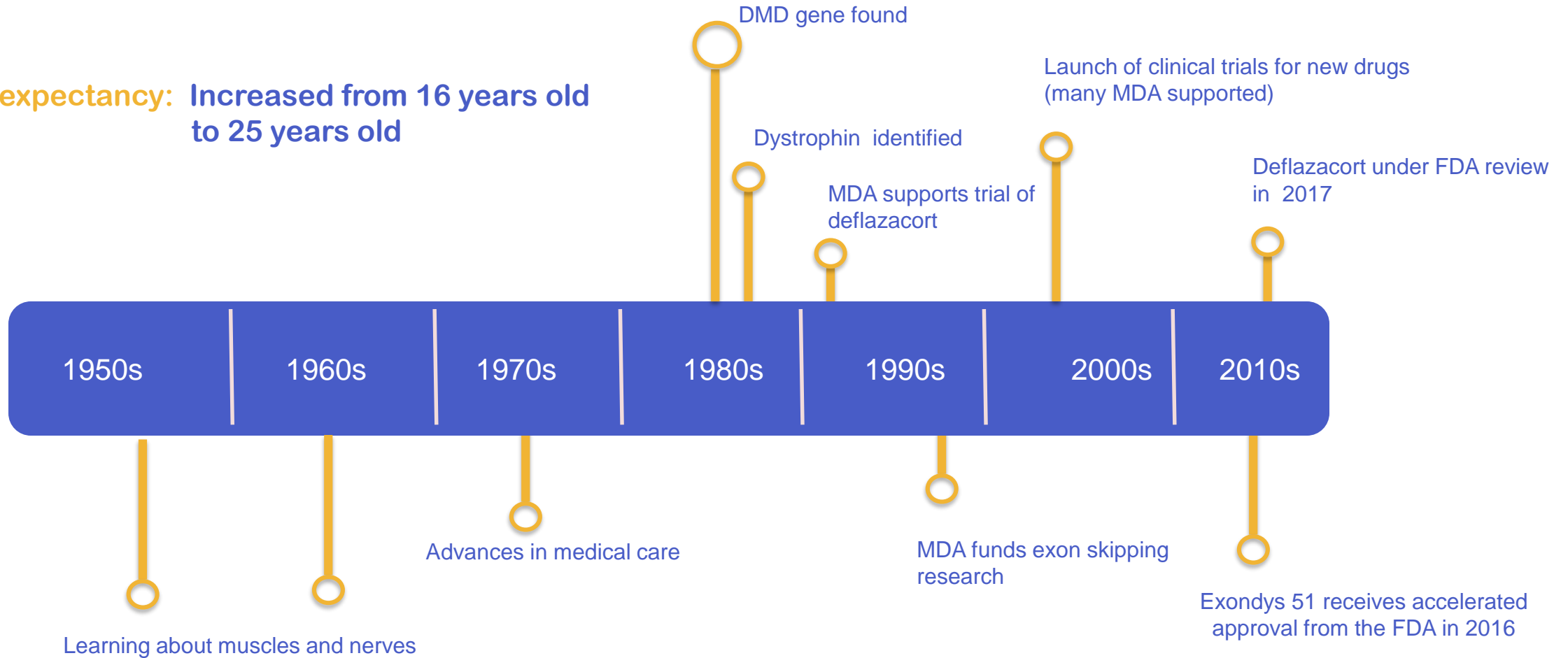
- MDA is committed to providing the “best week of the year” to more kids than ever before — our goal is to send a total of 20,000 kids to camp by the year 2020.
- MDA invests \$2,000 per year, per child, so campers and families can experience camp at no cost.
  - This investment to send kids to MDA Summer 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





# 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

Over the past **5**<sup>®</sup> years,  
MDA has supported

**151**<sup>®</sup>  
ALS grants  
with a total  
funding commitment of  
**\$44.8 million**<sup>®</sup>



Since 1950,<sup>®</sup>  
MDA has invested

**\$153.5 million**<sup>®</sup>  
in ALS research



MDA brings together the world's top researchers, clinicians, drug developers and industry partners to share ideas and updates

**MDA**<sup>®</sup>  
Scientific Conference

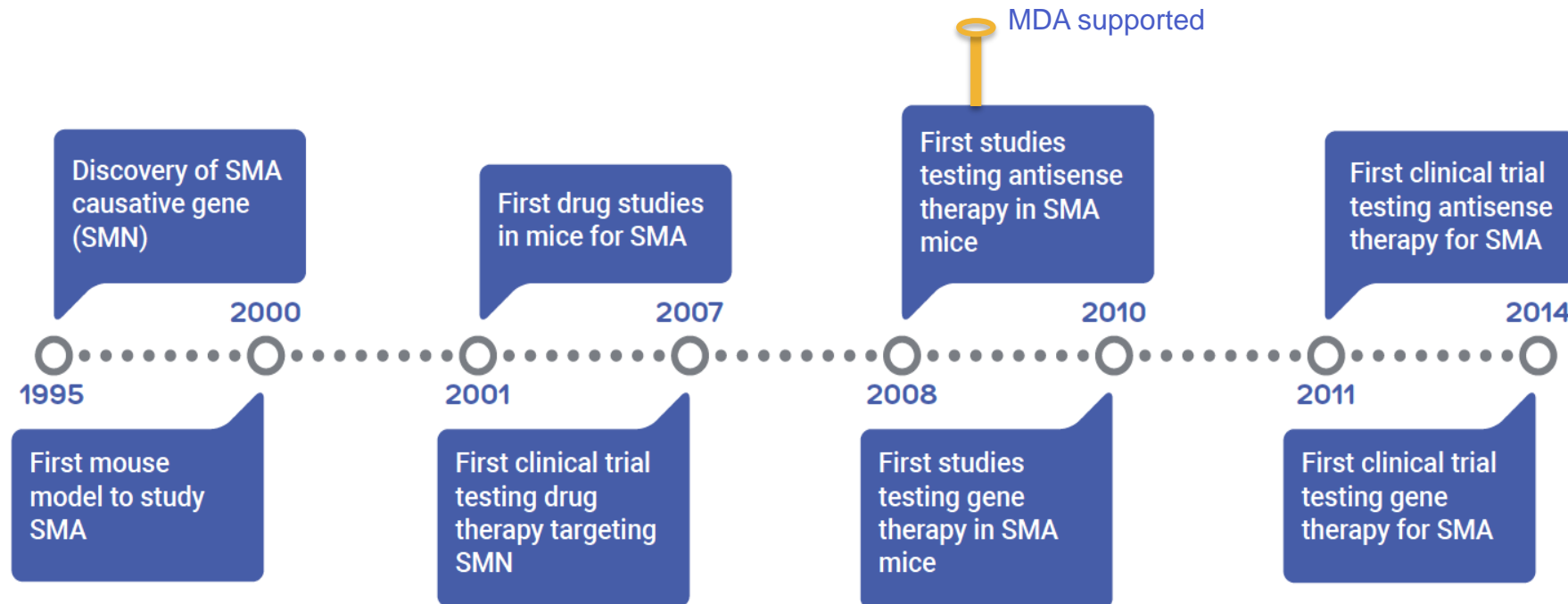
MDA currently has 33 active ALS research grants with a total funding commitment of \$8.8 million.

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.



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 19490Care Center

## Local Care Centers

- 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

- Tejvir 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

# MDA Maywood



## 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](mailto:atharp@mdausa.org), [edresnick@mdausa.org](mailto: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](http://www.mda.org)





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Thank You!

