



**2025**



# PARTNERSHIP IMPACT REPORT



## 75 Years of Impact. 71 Years of Partnership.

In 2025, the Muscular Dystrophy Association (MDA) marked its 75th anniversary, celebrating decades of progress for families living with neuromuscular disease. For 71 of those years, the International Association of Fire Fighters (IAFF) has stood alongside MDA through the Fill the Boot program, helping to raise more than \$721 million in support of our shared mission. What began in 1954 as a local act of service has grown into one of the longest-standing partnerships in the nonprofit sector, carried forward by generations of fire fighters committed to offering hope and a brighter future for families.

As MDA reflects on 75 years of impact, our partnership with the IAFF continues to evolve to meet emerging and urgent needs. In recent years, growing concerns about the potential link between firefighting and ALS have driven increased collaboration between our organizations. Building on the IAFF MDA ALS Initiative launched in 2024, our work remains focused on advancing ALS research within the fire service, developing fire fighter specific research efforts, creating accessible co-branded resources, and providing critical support to fire fighters and families affected by ALS. As IAFF General President Ed Kelly has emphasized, even after seven decades, the work is not done and fire fighters will continue to go where the fight is.

2025 also marked a new chapter for MDA with the appointment of Dr. Sharon Hesterlee as President and CEO. A seasoned leader in neuromuscular research and drug development, Dr. Hesterlee brings deep scientific expertise and a strong commitment to translating discovery into meaningful, everyday impact for families. As MDA looks to the future, guided by community voices and strengthened by long-standing partners like the IAFF, we remain focused on accelerating progress, expanding care, and ensuring no family faces neuromuscular disease alone.





## Edward A. Kelly

**General President,  
International Association of Fire Fighters**

“When we hold out a boot on the corner or outside a supermarket, we’re not just collecting change, we’re delivering hope to families living with neuromuscular disease. The IAFF is proud to fight for and with the MDA until a cure is found.”



## Dr. Sharon Hesterlee

**President and CEO,  
Muscular Dystrophy Association**

“It’s an honor to lead MDA at this pivotal moment. We have an extraordinary history of driving neuromuscular discovery and care. As we continue to turn those advances into meaningful everyday impact for families, we will also look to the future to develop and apply new technologies to the treatment of neuromuscular disease.”

## Science & Advocacy

For 75 years, MDA has been the nation's leading nonprofit driving research and innovation in neuromuscular diseases (NMDs), investing more than \$1.1 billion to date. This enduring commitment has fueled discoveries that led to more than 30 FDA-approved treatments in the past decade alone, transforming care and improving quality of life for individuals and families living with neuromuscular disease.

MDA's investment has also built the future of science by supporting over 7,000 investigators and training more than 2,000 early-career researchers, whose work continues to advance breakthroughs and bring strength and hope to the neuromuscular community.

Here are just a few highlights from 2025:

**6 new FDA-approved treatments were approved in 2025, bringing new hope to families living with neuromuscular disease**

**Duchenne muscular dystrophy added to the national newborn screening panel, working towards earlier diagnosis in all 50 states**

**6,021 individuals now contributing real-world data through MOVR, accelerating care improvements and treatment development**

**1,690 clinicians and scientists from 32 countries united to fast-track breakthroughs at the MDA Clinical & Scientific Conference**

**125 MDA advocates took to Capitol Hill to protect access to care, support medical research funding, and ease the burden on caregivers**

**Over \$2 million invested in collaborative research, advancing neuromuscular disease treatments**

# Treatments Approved for Neuromuscular Disease

1995

## RILUTEK®\*

Amyotrophic lateral sclerosis (ALS)

2006/2010

## MYOZYME/LUMIZYME®\*

Pompe disease

2015

## KEVEYIS®\*

Periodic paralysis

2016

## EXONDYS 51®\*

Duchenne muscular dystrophy (DMD)

## SPINRAZA®\*

Spinal muscular atrophy (SMA)

2017

## EMFLAZA®

Duchenne muscular dystrophy (DMD)

## RADICAVA®

Amyotrophic lateral sclerosis (ALS)

## SOLIRIS®

Myasthenia gravis (MG)

2018

## FIRDAPSE®

Lambert-Eaton myasthenic syndrome (LEMS)

2019

## ZOLGENSMA®

Spinal muscular atrophy (SMA)

## VYONDYS 53®

Duchenne muscular dystrophy (DMD)

2020

## EVRYSDI®

Spinal muscular atrophy (SMA)

## VILTEPSO®

Duchenne muscular dystrophy (DMD)

2021

## AMONDYS 45®\*

Duchenne muscular dystrophy (DMD)

## OCTAGAM® 10%

Adult dermatomyositis

## NEXVIAZYME®

Late onset Pompe disease (LOPD)

2022

## ULTOMIRIS®

Generalized myasthenia gravis (gMG)

## RADICAVA ORS®

Amyotrophic lateral sclerosis (ALS)

2023

## SKYCLARYS®

Friedreich's ataxia

## QALSODY®

Amyotrophic lateral sclerosis (ALS)

## VYVGART HYTRULO®

Generalized myasthenia gravis (gMG)

## ELEVIDYS®

Duchenne muscular dystrophy (DMD)

## RYSTIGGO®

Generalized myasthenia gravis (gMG)

2023 cont.

## POMBILITIM™ + OPFOLDA™

Generalized myasthenia gravis (gMG)

## ZILBRYSQ®

Generalized myasthenia gravis (gMG)

## AGAMREE®

Duchenne muscular dystrophy (DMD)

2024

## DUVYZAT®

Duchenne muscular dystrophy (DMD)

## EMFLAZA®\*

Duchenne muscular dystrophy (DMD)

2025

## EVRYSDI®

Spinal muscular atrophy (SMA)

## SOLIRIS®

Pediatric Myasthenia gravis (MG)

## IMAAVY™

Generalized myasthenia gravis (gMG)

## KYGEVVI®

Thymidine Kinase 2 deficiency (TK2d)

## ITVISMA®

Spinal muscular atrophy (SMA)

## UPLIZNA®

Generalized myasthenia gravis (gMG)



“Fill the Boot is deeply personal to me. I live with Thymidine Kinase 2 deficiency (TK2d), and because of MDA and dedicated fire fighters, a new treatment was approved by the FDA in 2025. This gives real hope to me and everyone living with this rare disease.”

**Branden Leimbach, MDA Ambassador**

## Care & Community

When MDA was founded in 1950, families living with neuromuscular diseases often faced their challenges in isolation, with few opportunities to connect or find meaningful support.

Today, MDA resources provide access to a continuum of care from the moment of diagnosis, ensuring that they have access to the highest standard of medical expertise and compassionate care.

MDA's programs bring people together, promoting a sense of connection and belonging. From programs like MDA Summer Camp, to initiatives that create shared experiences for families, to opportunities for learning, growth, and mutual support, these programs provide tools and resources that help families navigate the complexities of life with neuromuscular diseases while building strong, supportive networks.

MDA provides support through a national network of programs that provide care, connection, and hope:

**MDA Care Center Network**

**MDA Resource Center and MDA Connect**

**Quest Media Platform**

**MDA Scholarship Program and MDA Youth Mentorship Program**

**MDA Access Workshops, Next Steps Seminars, Engage Symposiums**

**MDA Peer Connections and MDA Community Groups**





## MDA Recreation Programs

MDA Summer Camp and MDA Family Getaways offer magical, barrier-free experiences that foster inclusion, independence, and lifelong friendships for kids, young adults, and families living with neuromuscular disease. Campers try new activities, develop confidence, and discover more of themselves, while Family Getaways provide accessible recreation and opportunities for connection within families and the neuromuscular disease community.

Fire fighters play a key role in bringing this magic to life. In 2025, 21 fire fighters served as counselors, guiding campers through activities and creating unforgettable experiences. Many more joined for Fire Fighter Day to see firsthand the impact they help make possible through Fill the Boot.

To learn more about MDA Summer Camp, visit [www.mda.org/summer-camp](http://www.mda.org/summer-camp).

### Camp Counselor Spotlight

Growing up, Thomas Beers watched fire fighters show up for his family during medical emergencies and at MDA Summer Camp, where his sister who lives with a rare form of Charcot-Marie-Tooth disease found friendship, freedom, and confidence. Seeing fire fighters serve both his family and the MDA community left a lasting impression that ultimately inspired Thomas to become a professional fire fighter and IAFF Local 2457 member in Montana.

Today, Thomas is carrying that legacy forward by leading his local to volunteer at MDA Summer Camp, even when it means traveling more than 13 hours. His local voted to send fire fighters as counselors and cover all costs, proving that when it comes to serving MDA families, fire fighters will always go the distance.

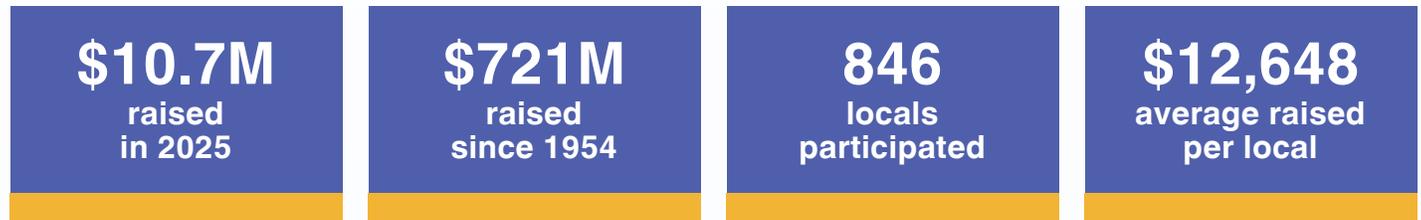
"My favorite thing about camp was connecting with the campers, learning their life stories, and giving them one week to take a break from reality and have fun. They can just go fishing, have water balloon fights, play, and be able to do things with no barriers. It's a life-changing opportunity."



# 2025 Fill the Boot Highlights

Thank you to every IAFF member who took part in Fill the Boot in 2025. This partnership, now more than 70 years strong, has raised over \$721 million for families living with neuromuscular disease. Every coin and bill in the boot continues to drive progress and change lives.

Thank you, IAFF, for your unwavering dedication to MDA's mission.



## Top 10 Locals

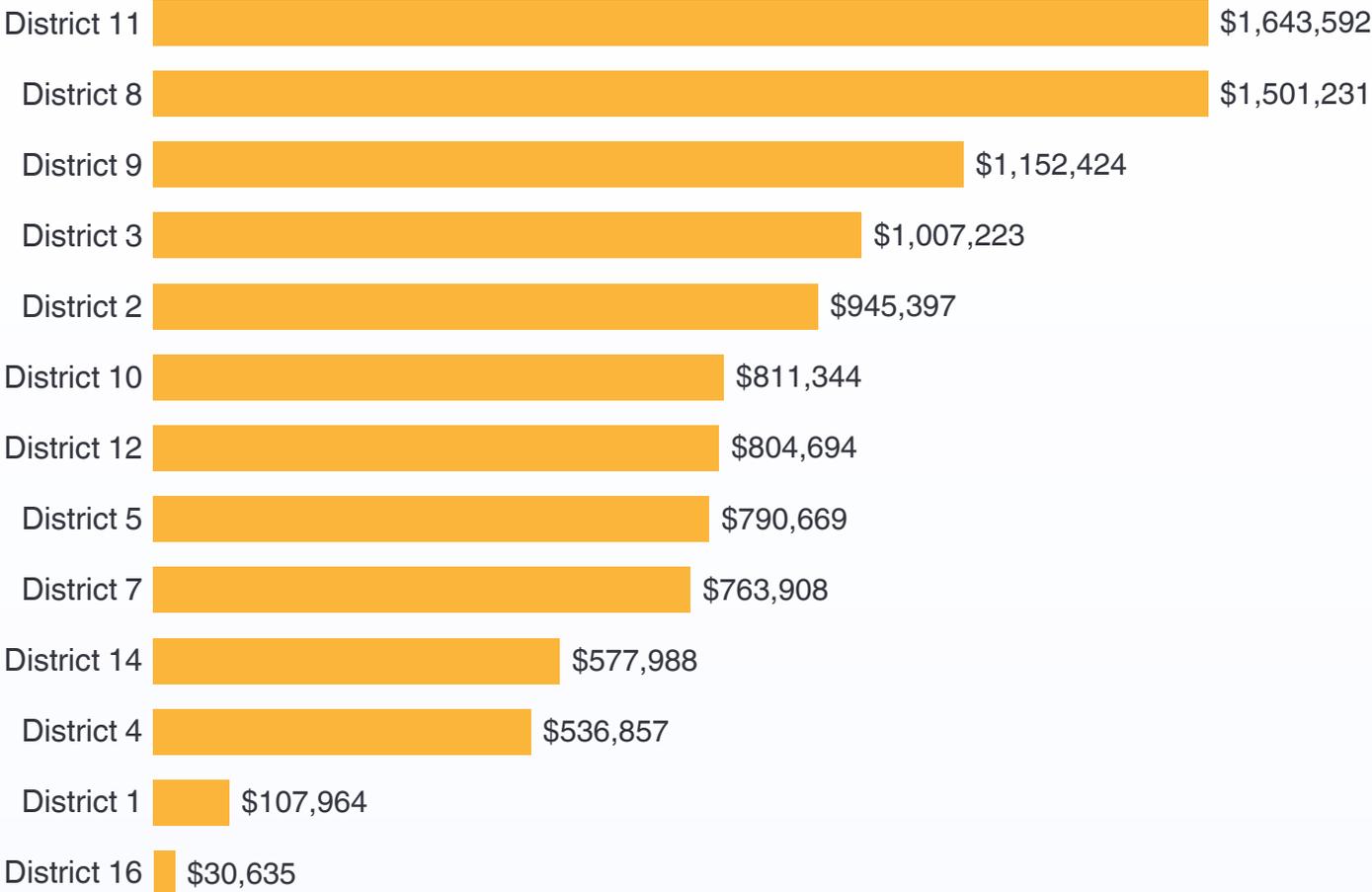
1. L2068 Fairfax County VA	\$206,476	6. L0058 Dallas TX	\$118,820
2. L2546 Suncoast FL	\$159,498	7. L2928 Palm Beach County FL	\$105,720
3. L0140 Nashville TN	\$152,828	8. L1264 Anchorage AK	\$102,917
4. L2665 Pro FFs of Eastern MO	\$137,071	9. L0936 Corpus Christi TX	\$101,836
5. L0493 Phoenix AZ	\$134,288	10. L0157 Oklahoma City OK	\$101,408

## Top 10 Locals per Member

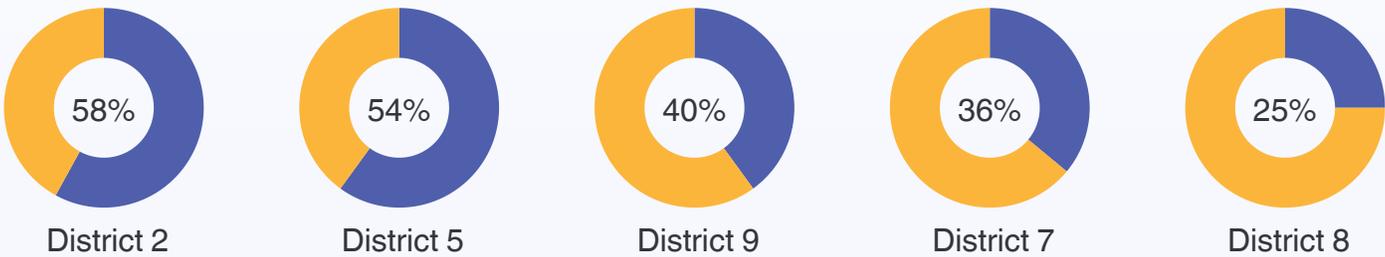
1. L5396 Bonneville County ID	\$3,256/mbr	6. L3464 Ontario OR	\$1,238/mbr
2. L0226 Marinette WI	\$2,668/mbr	7. L1159 Canby OR	\$1,120/mbr
3. F0116 Vandenberg CA	\$1,833/mbr	8. L2242 Glendive ME	\$1,088/mbr
4. L3429 Lewistown MT	\$1,400/mbr	9. L1935 Coon Rapids MN	\$1,060/mbr
5. L4099 Tahlequah OK	\$1,348/mbr	10. L4564 McCall ID	\$1,015/mbr



# Districts Ranked



# Top District Participation



## Event Spotlight

Organized by a dedicated committee and PFFNH Locals, the annual Trans-New Hampshire Bike Ride brings together fire fighters, cyclists, and community members to ride across the state in support of MDA. In 2025, the event celebrated 38 years of making an impact. The ride has contributed more than \$3 million to MDA’s mission since it started.



# Why Fill the Boot?

For more than 70 years, fire fighters have answered the call for MDA families through Fill the Boot. It is more than a fundraiser. It is a tradition that strengthens your local, connects you with your community, and fuels life-changing progress.

Fill the Boot brings:

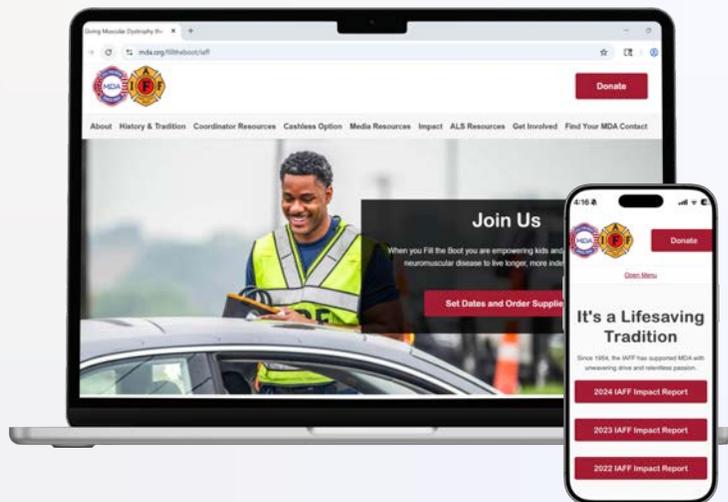
- Tradition** – 70+ years standing with MDA
- Ease** – Turnkey program, no-cost supplies
- Visibility** – Positive, public-facing engagement
- Competition** – Out-raise neighboring locals
- Altruism** – Make a real difference
- Comradery** – Unite your crews
- Personal Connection** – Support someone you know

## Fill the Boot Toolkit Spotlight

Planning a boot drive has never been easier. The Fill the Boot Toolkit puts everything your local needs in one place, with ready-to-use resources available via computer or mobile.

Inside the toolkit you'll find:

- Planning checklists and safety resources
- Customizable posters, flyers, and social media guides
- Sample emails and talking points
- Tips to boost visibility and increase dollars in the boot



Start planning today: [www.mda.org/filltheboot/iaff](http://www.mda.org/filltheboot/iaff)





Muscular  
Dystrophy  
Association

## Join the Community

 Instagram: @mdaorg

 Facebook: MDAorg

 X: @MDAorg

 LinkedIn: Muscular Dystrophy Association

 YouTube: YouTube.com/MDA

 Advocacy X: @MDA\_Advocacy

 TikTok: @mdaorg

 Twitch: MDA\_LetsPlay

 Discord: MDA Let's Play

## Get Involved



From Fill the Boot to MDA Summer Camp and everything in between, your MDA Contact is your go-to resource for tools, support, and ideas to make the biggest impact in your community.

**Scan the QR code to reach out, get your questions answered, and join the MDA Community today.**