

#MDABootCamp



For Strength,  
Independence & Life



BOOT

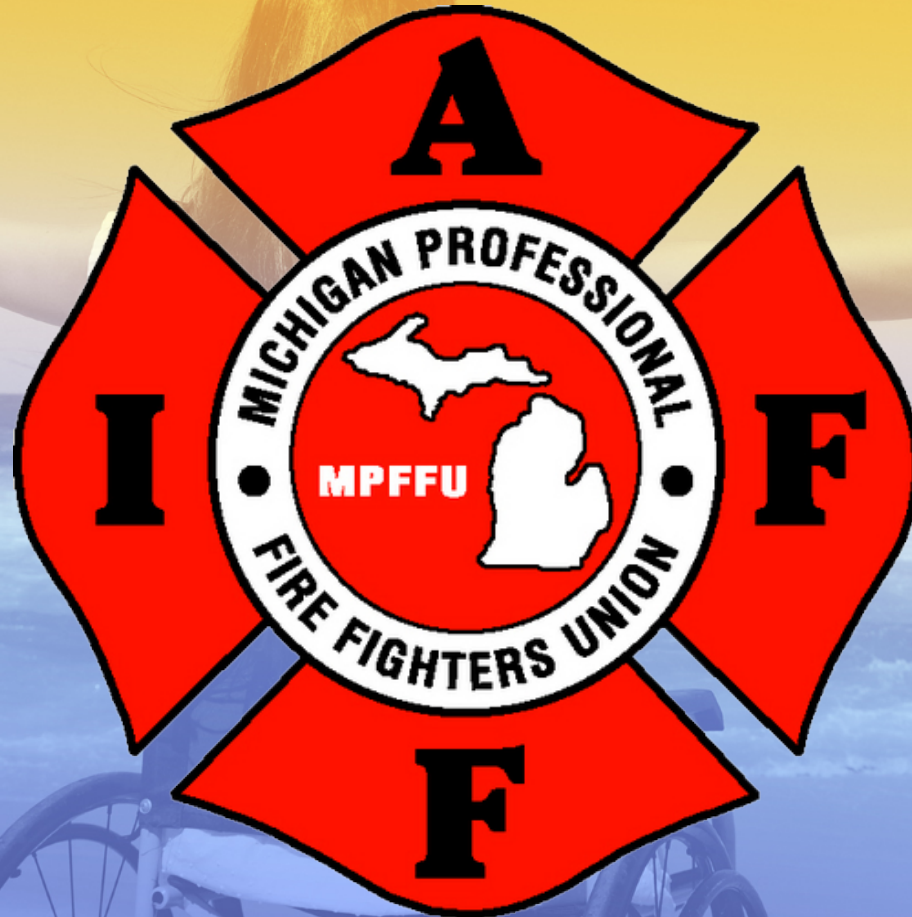
CAMP



April 18, 2019



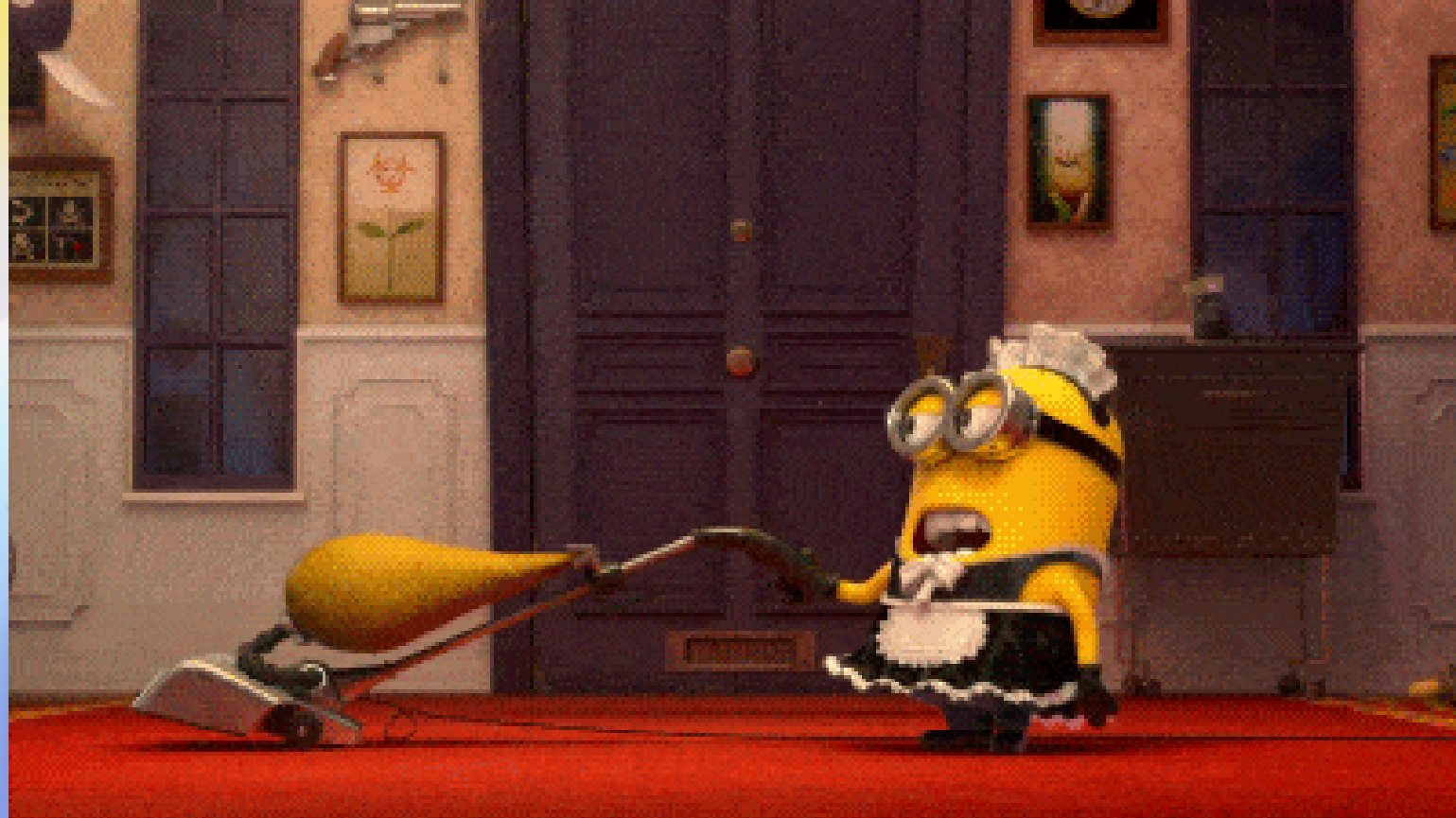
WELCOME



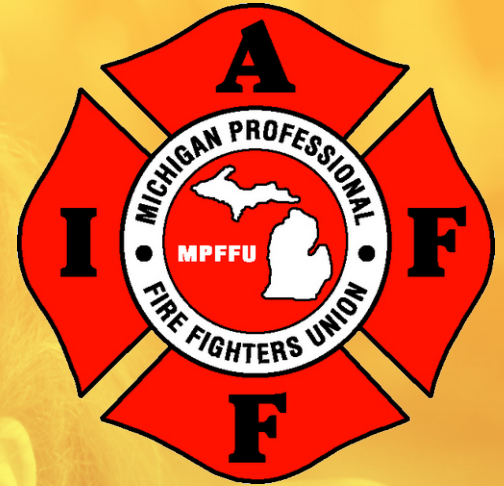
# IN MEMORIUM



# HOUSEKEEPING



# AGENDA



- 12:30-1:00pm Arrival and Registration
- 1:00-2:00pm Welcome
- 2:00-3:00pm Safe and Effective Boot Training
- 3:00-4:00pm Picture Frame Making with Patients
- 4:00-5:00pm Awards/Closing
- 5:00-6:00pm Intermission (Appetizers / Cash Bar)
- 6:00pm Dinner (Clubhouse BBQ )

• 6:05pm



VS.



# MDA STAFF

## MDA Regional Manager for Firefighter Partnerships

Jennie King

### ***Greater Michigan Office:***

- Cindy Clark-Executive Director
- Amanda Wentzloff-Development Director
- Jaimie Capen-Development Coordinator
- Matthew Jostock-Development Assistant
- Jacquie Palka-Care & Clinical Services Specialist

2133 University Park Drive Suite 400

Okemos, MI 48864

517-706-0348

### ***Greater Detroit Office:***

- Brian Springett-Executive Director
- Aaron Lewber-Development Specialist
- William Hamilton-Development Coordinator
- Kendra Kroll-Development Assistant
- Maggie Segal-Care & Clinical Services Specialist
- Sharon Myers-Care & Clinical Services Specialist

950 Stephenson Hwy Suite 209

Troy, MI 48083

734-416-7076

2018 TOTAL \$ RAISED

Thank you!

\$305,484

# PER CAPITA

2016 – MPFFU Participation - 27%

2017 – MPFFU Participation - 32%

2018 – MPFFU Participation - 42%

- 2018 MPFFU/IAFF Per Capita - \$62.23
- 2019 MPFFU/IAFF Per Capita Goal - \$81.48 (\$400,000)



**TERRY CHESNEY**



**Secretary Treasurer  
Michigan Professional Fire Fighters Union**



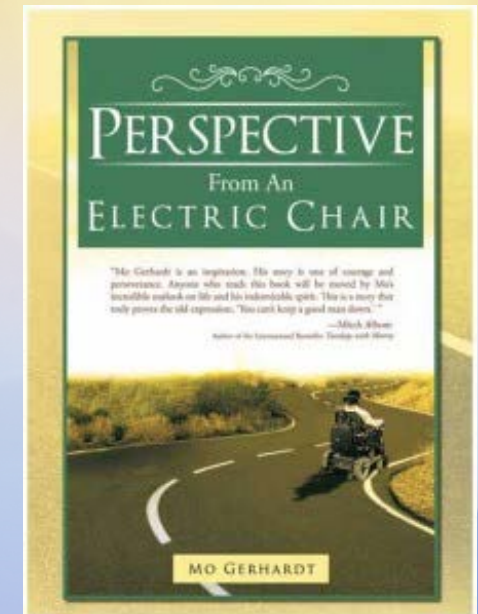


# MO GERHARDT



**Michigan State University  
Academic Student Affairs  
Advisor**

**Author :  
Perspective  
from an  
Electric Wheel Chair  
MoGerhardt.com**



# 65 YEARS STRONG





- For 65 years, Fire Fighters have mobilized communities in support of MDA



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- 1,900 Fill the Boot events raising over \$20M in 2018

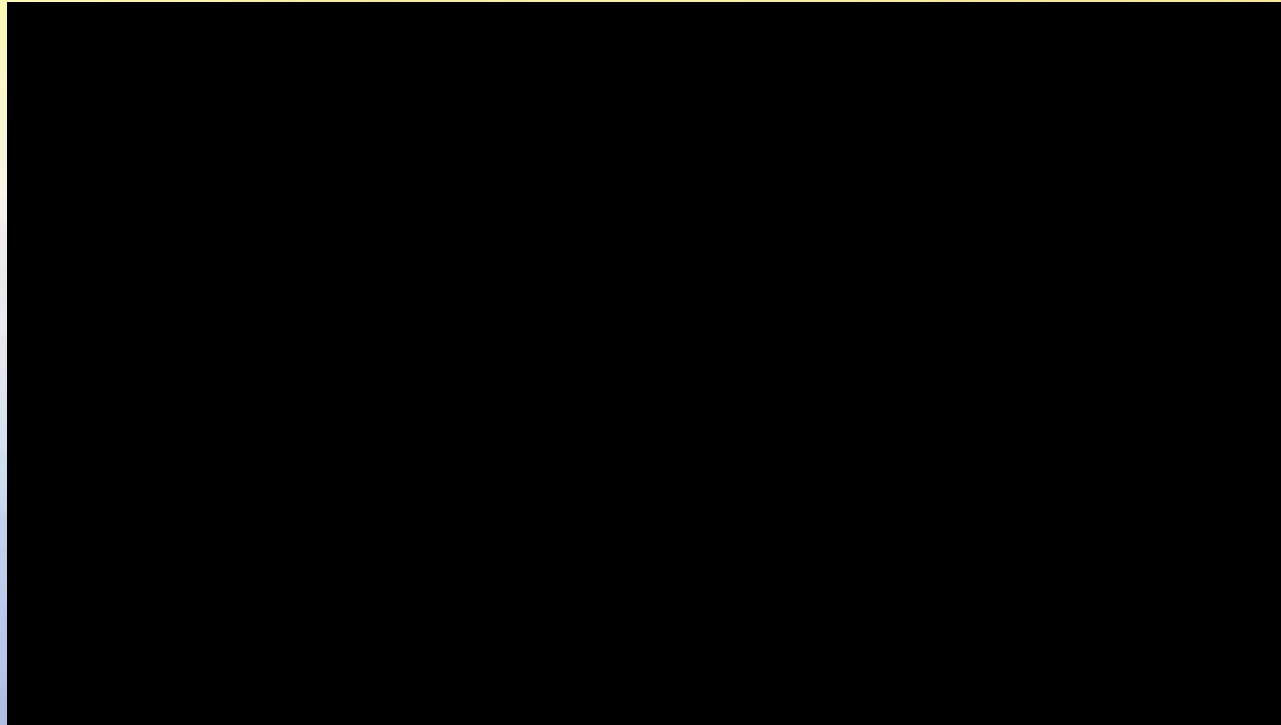


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- 1,900 Fill the Boot events raising over \$20M in 2018
- >100,000 volunteer participants
- \$650 million raised

65 YEARS STRONG





# ROGER LOPEZ



**IAFF MDA  
COORDINATOR**



**MDA<sup>®</sup>**

Mission & Research  
Update



YOU

HAVE HELPED BRING NEW  
TREATMENTS

FORWARD

# Innovations in Science

We are accelerating the development of therapies and cures

## RESEARCH

MDA is the largest source of funding for neuromuscular disease research outside the federal government and has invested more than \$1 billion since its inception

## THERAPIES

Research supported by MDA is directly linked to life-changing therapies across multiple neuromuscular diseases

## TECHNOLOGY

MOVR is the first and only data hub that aggregates clinical, genetic and patient reported data for multiple neuromuscular diseases to improve health outcomes and accelerate drug development

## Innovations in **Care**

We provide programs and services that enrich the lives of people with neuromuscular disease

### CARE CENTERS

We support the largest network of multidisciplinary clinics, providing best-in-class care at more than 150 of the nation's top medical institutions

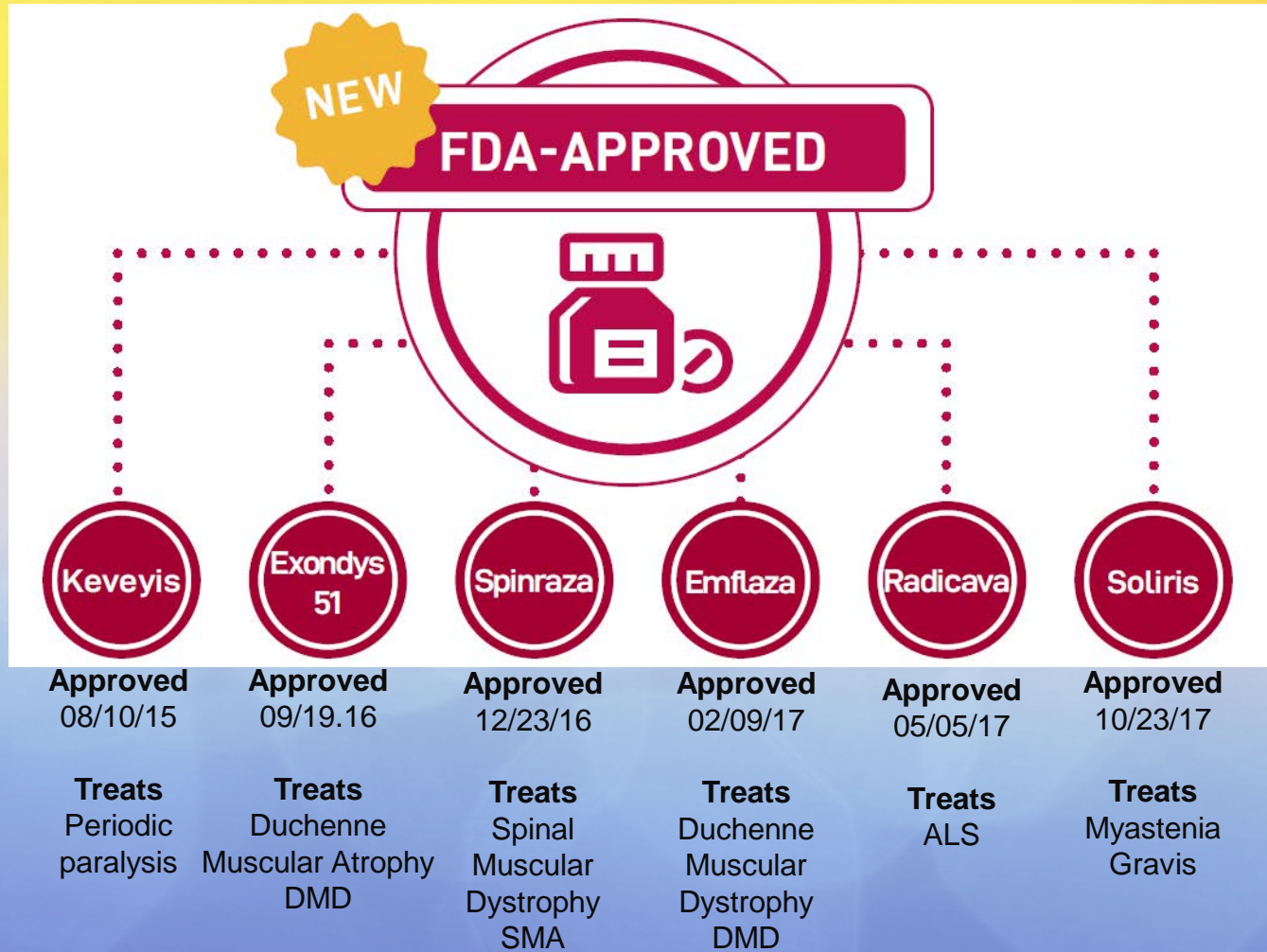
### RESOURCES

Our Resource Hub serves the community with one-on-one specialized support and we offer educational conferences, events, and materials for families and healthcare providers

### RECREATIONAL PROGRAMS

Each year thousands of children and young adults learn vital life skills and gain independence at summer camp and through recreational programs, at no cost to families

## Time of Unprecedented Progress



- Research activity is strong
- Robust pipeline of potential therapies
- Guidelines for care being developed
- Therapies being approved
- Newborn screening expanding
- 175+ active research projects worldwide
- 2017 – 221 active grants totaling \$54M dollars
- \$1B invested since inception



# Transforming and Saving Lives

These new drugs could provide significant benefits to individuals living with muscular dystrophy, ALS and related diseases to help transform their lives.



They may slow functional decline

+



They could help maintain strength and function longer

+



They may even improve the ability to perform daily activities

=



Resulting in enhanced quality of life and potentially, for some, a longer life span

## Care Center Impact



140+ full time MDA staff actively support care centers



200+ appointment locations



Tens of thousands of annual appointments



Serve as major centers of clinical trial activity across the US



Actively providing clinical and genetic insights through MOVR



# Transforming Lives Together for Over 65 Years



## 1954

President Redmond declares IAFF will support MDA until a cure is found  
1st Fill the Boot campaign in Massachusetts

1st MDA summer camp 1955

\$250,000 raised 1960

1970 \$1 million raised

\$2 million raised 1975

1980 \$3 million raised

1990 \$8 million raised

NEW ERA: Harold Schaitberger elected IAFF General President 2000

## 2004

\$20 million raised in IAFF/MDA 50th Anniversary

1st FDA-approved ALS treatment 1995

Myozyme approved by the FDA for the treatment of Pompe disease 2006

Dozens of clinical trials in progress 2014 as direct result of MDA research

2014 IAFF and MDA celebrate partnership's 60th Anniversary

2016 FDA approves Spinraza, which treats Spinal Muscular Atrophy (SMA)

2018 \$650 million raised since IAFF/MDA partnership began

## 2016

FDA granted accelerated approval for the first drug for Duchenne muscular dystrophy and the first disease-modifying drug for spinal muscular atrophy

2017 FDA approves second drug for Duchenne muscular dystrophy, Radicava, which treats ALS and Soliris, which treats Myasthenia Gravis

## 2019

IAFF and MDA celebrate 65 years of a strong partnership

2019 MDA and the IAFF combine their efforts to promote and implement newborn screenings across the country, so every baby born with neuromuscular disease has access to the necessary treatments and support services to help them live longer, healthier lives.

## 1966

1st Jerry Lewis Telethon, raising \$1 million

## 1986

1st ALS clinic opens  
Duchenne muscular dystrophy gene/protein identified

MDA opens its 100th clinic 1977



Thank You for helping  
Give Strength



**MATTHEW GREINER**



**2019 MDA  
Michigan  
Goodwill  
Ambassador**



BREAK



# SAFE AND EFFECTIVE BOOT DRIVES





# COORDINATOR TOP 10 TIPS TO SUCCESS



- Know the mission
- Be a planner
- Get reliable committee members
- Set specific goals
- Determine the how's and when's
- Foster cooperation through communication
- Track progress
- Be a problem solver
- Believe in the goal!
- HAVE FUN!!





# LOCATION-LOCATION-LOCATION



- Key Intersections
  - Visible
  - Timing- lights, traffic flow
  - Is there places for signage
- Sports Stadiums or Festivals (events)
- Have a back up plan for calls or bad weather
- Discuss alternative dates

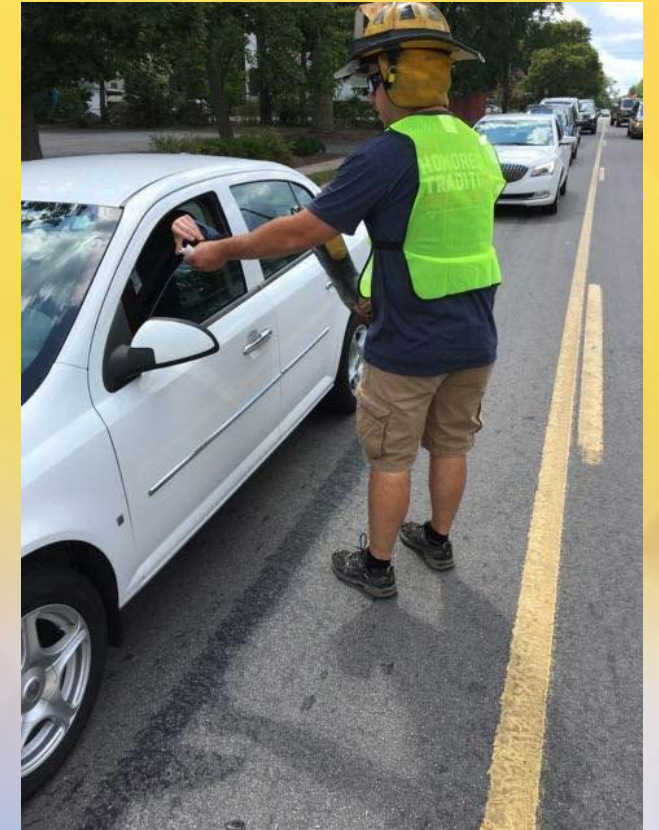




# PLAN FOR SUCCESS DAYS-TIMES-LOCATION



- MPFFU Statewide Weekend
- Find what works for you
- Determine the best time and staff accordingly
- Clear training schedule
- Set up Media Involvement







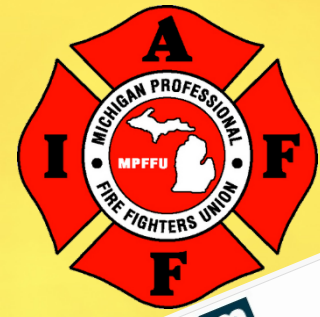
# WORKING WITH MUNICIPALITIES



Cooperation from government and local politicians is essential.

- Know the ordinances
- Develop a game plan with Union leadership and MDA
- Get endorsements from city, county and state officials
- Attend key state/city/local meetings with MDA staff and family
- Provide media opportunities & public acknowledgement
- Be prepared for changes in legislation, HB 4160 now PA 112 of 2017





# OVERCOMING OBSTACLES



Act No. 112  
Public Acts of 2017  
Approved by the Governor  
July 27, 2017  
Filed with the Secretary of State  
July 27, 2017  
EFFECTIVE DATE: July 27, 2017

**STATE OF MICHIGAN  
99TH LEGISLATURE  
REGULAR SESSION OF 2017**

Introduced by Reps. Hernandez, Lucido, Canfield, Frederick, Noble, Brann and Sabo

## ENROLLED HOUSE BILL No. 4160

AN ACT to amend 1949 PA 300, entitled "An act to provide for the registration, titling, sale, transfer, and regulation of certain vehicles operated upon the public highways of this state or any other place open to the general public or generally accessible to motor vehicles and distressed vehicles; to provide for the licensing of dealers; to provide for the examination, licensing, and control of operators and chauffeurs; to provide for the giving of proof of financial responsibility and security by owners and operators of vehicles; to provide for the imposition, levy, and collection of specific taxes on vehicles, and the levy and collection of sales and use taxes, license fees, and permit fees; to provide for the regulation and use of streets and highways; to create certain funds to provide penalties and sanctions for a violation of this act; to provide for civil liability of manufacturers, the manufacturers of certain devices, the manufacturers of automated technology, upfitters, owners, and operators of vehicles and service of process on residents and nonresidents; to regulate the introduction and use of certain evidence; to regulate and certify the manufacturers of certain devices; to provide for approval and certification of installers and servicers of certain devices; to provide for the levy of certain assessments; to provide for the enforcement of this act; to provide for the creation of and to prescribe the powers and duties of certain state and local agencies; to impose liability upon the state or local agencies; to provide appropriations for certain purposes; to repeal all other acts or parts of acts inconsistent with this act or contrary to this act; and to repeal certain parts of this act on a specific date," by amending section 676b (MCL 257.676b).

*The People of the State of Michigan enact:*

- Sec. 676b. (1) Subject to subsection (2), a person, without authority, shall not block, obstruct, impede, or otherwise interfere with the normal flow of vehicular or pedestrian traffic upon a public street or highway in this state, by means of a barricade, object, or device, or with his or her person. This section does not apply to persons maintaining, rearranging, or constructing public utility facilities in or adjacent to a street or highway.
- (2) Subsection (1) and any provision of the Michigan Administrative Code that prohibits a person from standing in a roadway other than a limited access highway for the purpose of soliciting a ride, employment, or business from the occupant of any vehicle do not apply to a person who is soliciting contributions on behalf of a charitable or civic organization during daylight hours, if all of the following are satisfied:
  - (a) The charitable or civic organization complies with applicable local government regulations. A local government may enact or enforce regulations restricting, but not prohibiting, the activity described in this subsection.
  - (b) The charitable or civic organization maintains at least \$300,000.00 in liability insurance.
  - (c) The person is 18 years of age or older.
  - (d) The person is wearing high-visibility safety apparel that meets current American standards promulgated by the International Safety Equipment Association.
  - (e) The portion of the roadway upon which the solicitation occurs is not a work zone and is within an intersection where traffic control devices are present.

- ~~Prohibitive Ordinances~~
- Chief won't allow it
- Low Morale/Participation
- Construction
- What are you running into?
- County wide blitz





# PROMOTION AND MARKETING



Helping your Local receive publicity by targeting the public, media and government leaders



Newspaper and print media  
Radio  
Television  
Web sites  
Event promotional material  
Press Conferences





# 2019 Fill the Boot Materials



Toll Sign



**AHEAD**  
**Fire Fighter**  
**Fill the Boot®**  
**to Benefit**

**MDA®**

Muscular Dystrophy Association • mda.org



Caution Sign



Safety Vest

Sticker



# SAFETY PLANS



Safety must be our #1 priority!

A Fill-the-Boot safety plan must be in place for all participating departments; your local MDA office can assist in creating a safety plan for your event.

Signage, cones, **safety vests**, apparatus and sufficient fire fighters will help ensure a SAFE and FUN event for all participants.

MDA Insurance Policy





# DAY OF....



- Call dispatch in the morning to remind them of Fill the Boot and direct any complaints to you.
- Call ahead to all radio and TV stations, they will usually give a last minute shout out on air.



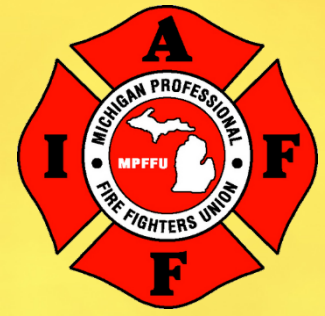


# SAFETY FIRST



- Wear safety vests or reflective material
- Intersections should be well marked with cones
- Post MDA banners well ahead to alert oncoming traffic
- Parked apparatus should be highly visible
- Hydrate - hydrate - hydrate





# MORE SAFETY TIPS



- Never stop traffic and only approach stopped vehicles
- Always maintain a professional attitude
- Spouses and children should not be allowed to collect in the streets
- BE ALERT!







# INSURANCE



- **Who:** All active and retired Firefighters, Cadets, Firefighters in training, and EMT's working on duty or off, who are 18 yrs of age or older, on behalf of the Policyholder
- **When:** On the premises if attending or participating in a covered activity; including travel without deviation or interruption between home and the site of the covered activity



# SECURING FUNDS



- Contact all stations or kick off points make sure all supplies are delivered and organized.
- Make a plan to safeguard the bags of money
- Prior to FTB, meet with Local's bank representative to arrange the counting and depositing of funds
- Obtain money bags, seals, wrappers and ID tags, or make your own





# SECURING FUNDS



- Arrange money pick-ups from corners and deposit schedules
- Determine system to track individuals, shifts and station collections
- Provide specific instructions in writing
- Establish a safe secure area to handle funds



# Social Media

## Stay Connected!



Muscular Dystrophy Association

 [mda.org](http://mda.org)

 [facebook.com/MDAnational](https://facebook.com/MDAnational)

 [@MDAnews](https://twitter.com/MDAnews)



# Social Strategy

1. #1 shared content = PHOTOS
2. Tag and mention related people/groups
3. *Call-to-action* (“Stop by TODAY to help #FillTheBoot!”)
4. Hashtags!

**#FillTheBoot #[LOCAL] @IAFFnewsdesk #[CITY]**

5. Facebook LIVE



# Facebook LIVE



1. Tell people *when* you'll be broadcasting ahead of time
2. Go Live when you have a strong connection
3. Capture attention with a catchy description about your broadcast
4. Respond to comments and mention people by name
5. Broadcast longer to reach more people (10 min. recommended)
6. Use a closing line to end broadcast



# CONNECT – Facebook



MDA MPFFU

@MDAMPFFU



Greater Michigan MDA

@OkemosMDA



MDA Greater Detroit

@MDAGreaterDetroit

After you **like** your local MDA page, *share* or leave a *review*!



# MPFFU WEBPAGE AND MOBILE APP





# SOCIAL BADGES



Cover Photo

65 YEARS STRONG



#FillTheBoot



#FillTheBoot

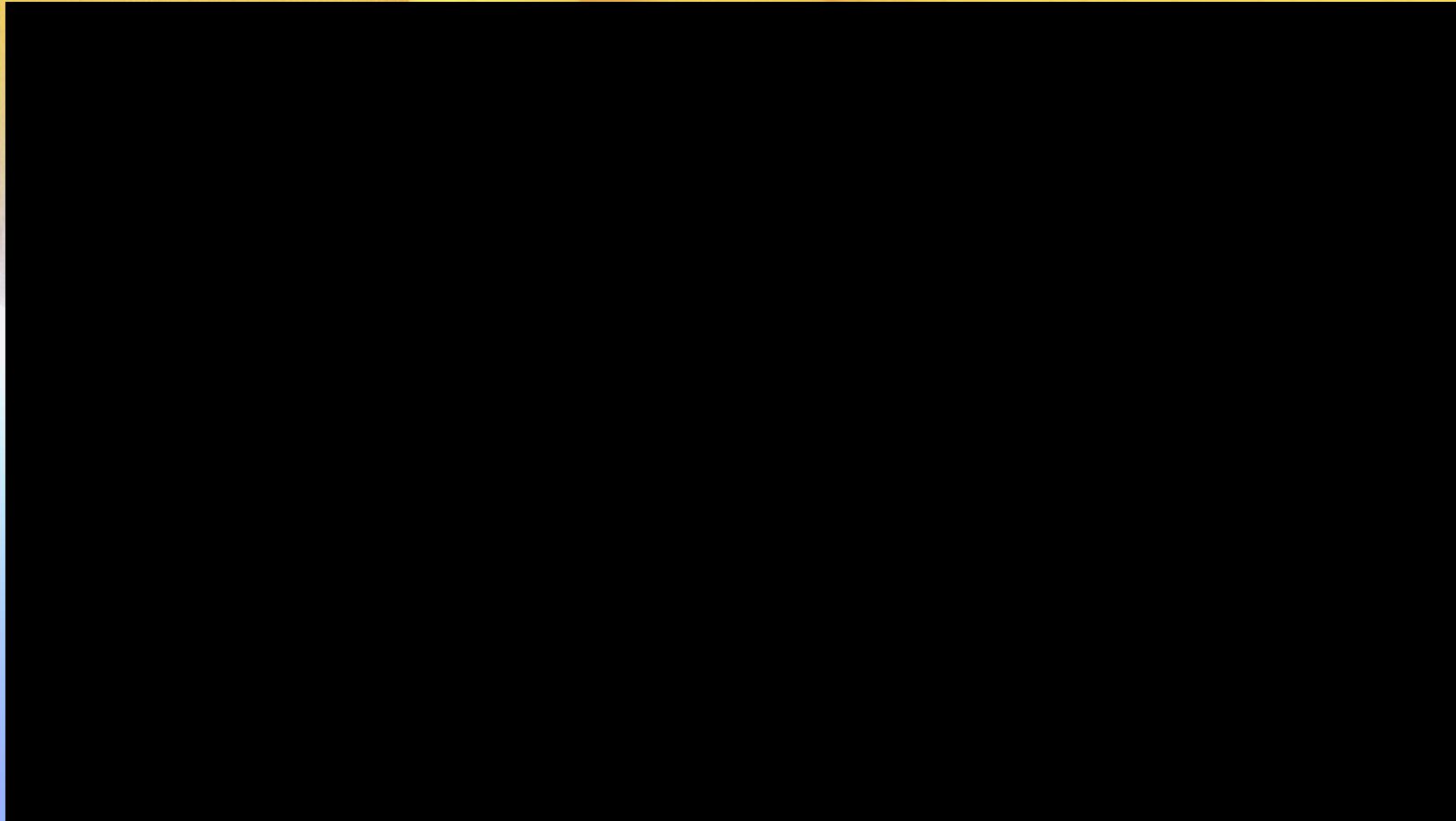
Social Badges



BREAK



# 2018 FILL THE BOOT



# AWARDS



# BOB McALVEY



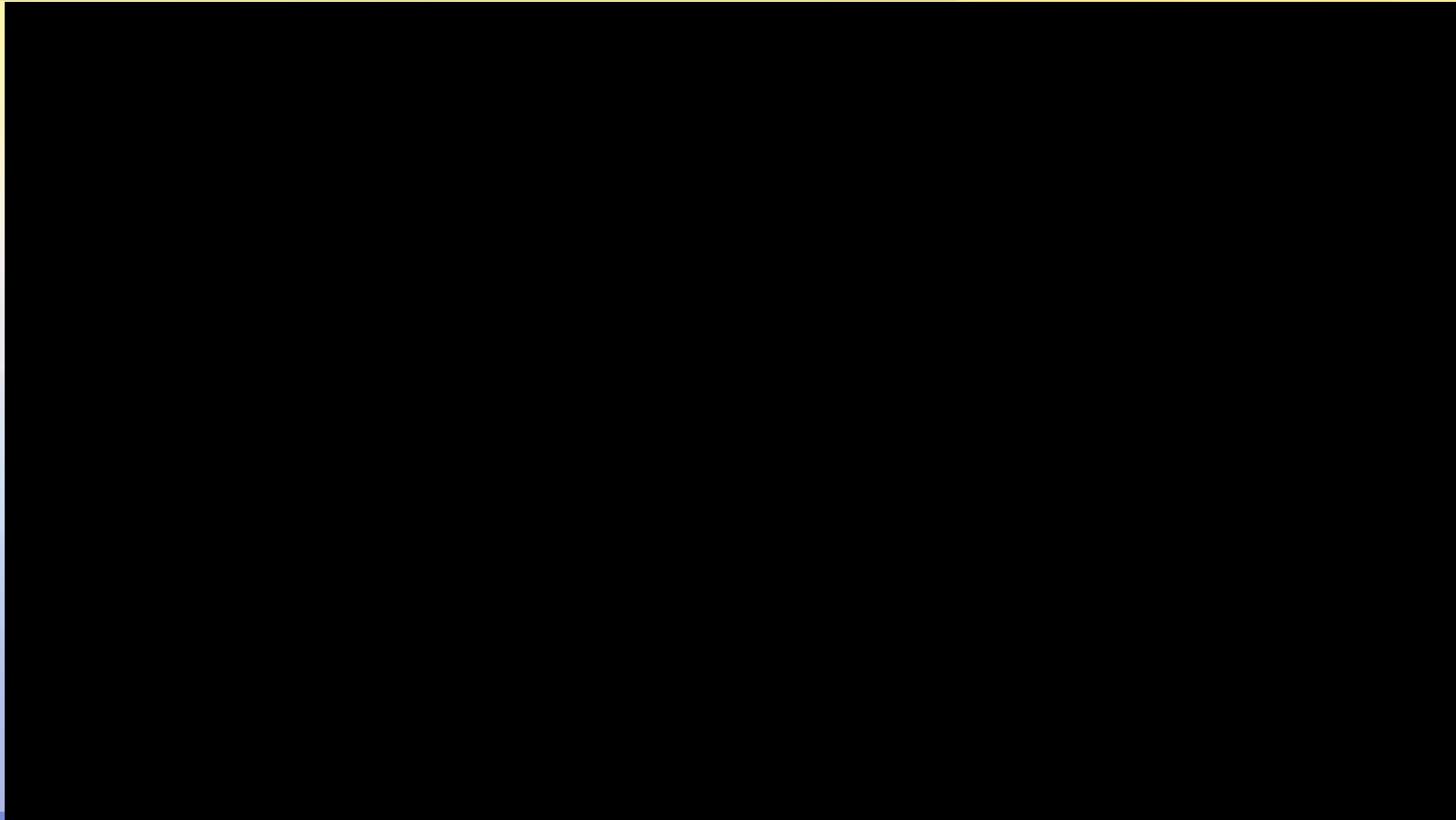


**Captain Robert McAlvey**

IAFF Local 1600

Meridian Professional Fire Fighters Association

# SUMMER CAMP



# MDA Summer Camp VIP Day

## *Save the Date!!*



### **Camp Sherman Lake YMCA**

Tuesday, June 18<sup>th</sup>, 2019

10:00 a.m.- 4:30 p.m.

6225 N. 39th

Augusta, MI 49012

### **Camp Cavell**

Sunday, June 23<sup>rd</sup>, 2019

11:00 a.m. – 3:00 p.m.

3335 Lakeshore Rd

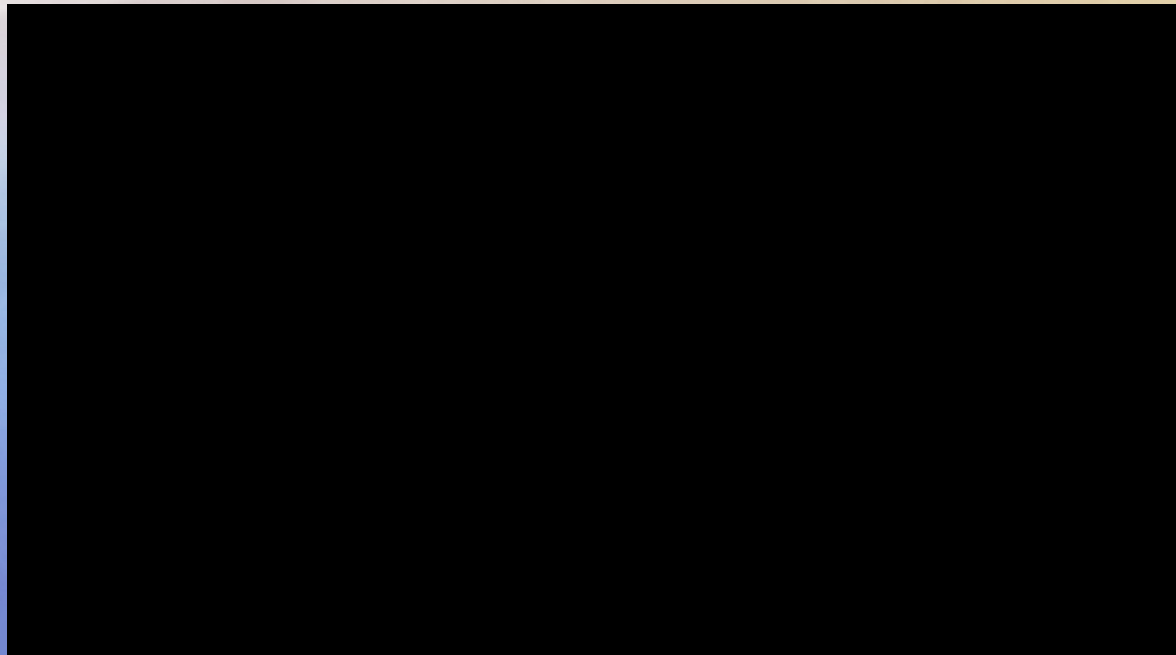
Lexington, MI 48450

***Please join us!***





**You are helping kids and adults with  
muscle-debilitating diseases  
live longer and grow stronger!**



# Thank you!

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muscle-debilitating diseases  
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