



# 2022 IAFF

## Impact Report

# A LETTER FROM MDA'S PRESIDENT & CEO

To the International Association of Fire Fighters,

It goes without saying that the world around us has changed over the past two years in ways we never could have imagined. Fortunately, the search for neuromuscular disease (NMD) treatments was able to move forward throughout the pandemic as research laboratories and clinical trials quickly adapted to our new realities.



The Muscular Dystrophy Association's (MDA) mission to empower the people we serve to live longer more independent lives continued and is happening right now through the ever-expanding pipeline of promise - 18 FDA approved drugs for NMD in the last 12 years. Those treatments were created from MDA's vision to open a new field of medicine and push the boundaries of the medical frontier we call genetic medicine.

In the 21st century, MDA leads the way in developing treatments and cures on that new medical frontier. For virtually all human history, people with a genetic disease had no hope of a treatment. People with progressive genetic diseases – the ones that get worse over time like muscular dystrophy and most NMDs – had no hope of even slowing their disease's relentless progress and gaining a longer life. Today, however, for the first time in history and for the first time in medicine, MDA-supported scientists and clinicians are helping develop the first FDA approved treatments for genetic diseases that are stopping some and slowing many others.

MDA also leads the way in caring for people living with NMD. Our nationwide network of MDA Care Centers is staffed with the nation's top NMD physicians who specialize in the diagnosis and treatment of patients with NMD. It is a network of physicians, nurses and other healthcare specialists unique in the United States for their expertise in helping patients with muscular dystrophy, spinal muscular atrophy, amyotrophic lateral sclerosis (ALS), and many dozens of other muscle-wasting diseases live lives to their fullest potential.

What is equally important is that MDA's nationwide clinic network of NMD specialists are not only connected to the latest clinical trials and FDA approved treatments, but many are also among the leaders in developing new treatments and creating the pipeline of progress that is the hallmark of today's NMD frontier.

Hope for a longer, more independent life is now becoming a reality for thousands of patients with muscular dystrophy and related diseases. And the pipeline of promise – more life empowering treatments and cures – is growing and creating ever more hope for the millions of patients and their families who are at the heart of MDA's mission and vision.

With the IAFF's support, you and MDA are leading the way. Please watch our mission video where we celebrate our community and the progress we have made, together.

Sincerely,

A handwritten signature in blue ink that reads "Donald S. Wood".

**Donald S. Wood, PhD**

President and CEO

Muscular Dystrophy Association

Watch our Mission Video at [mda.org/missiontribute](https://mda.org/missiontribute)

# MDA'S 70 YEARS OF IMPACT

MDA began in 1950 in New York City from a single family who had a child with muscular dystrophy. They could find only one clinician, in all of America, who specialized in studying muscular dystrophy, a genetic disorder. Going door-to-door, apartment-to-apartment, they raised a few thousand dollars and gave it to that one clinician. MDA's focus on research, on gaining new knowledge to treat a disease where no one had much, if any, knowledge - began at that moment.

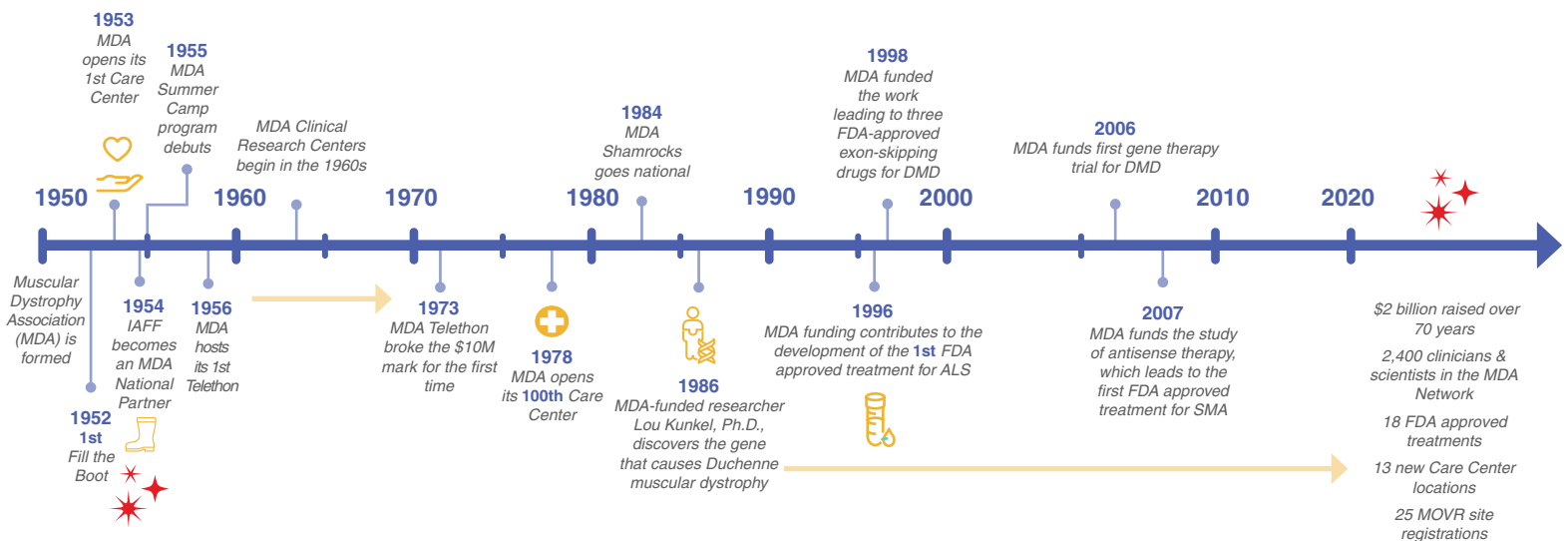
From that small beginning, donations over the next 70 years have risen to more than \$2 billion and MDA, through its more than one billion dollars of research support and over 2,000 clinicians and scientists brought into the field through training, scholarship and fellowship grants, is rightly credited with founding the medical specialty we now know as Neuromuscular Disease Medicine.

A major step forward for patients was MDA's early linkage of patient care and scientific research in a single environment known as MDA Clinical Research Centers. This environment brought together the best neuromuscular disease clinicians and scientists – trained through MDA funding – in collaborative projects to address diagnostic and treatment issues. In hindsight, this set the stage for what we now know as genetic medicine, which requires collaboration not just of clinicians and scientists, but also patients. From the beginning of MDA's Clinical Research Centers in the 1960's, patients and their families have been involved in virtually every diagnostic and treatment advance.

The major turning point in MDA-supported efforts to advance both diagnosis and treatment occurred in 1986 with discovery of the gene and its defects that caused Duchenne muscular dystrophy in some cases and Becker muscular dystrophy in other cases. This was followed in 1987 with identification of the protein, named dystrophin, that was normally made by the single gene underlying both diseases. The dystrophin gene, as it is now called, remains the largest known gene in the human genome. Its discovery marked a milestone in both muscular dystrophy research specifically and in genetic research generally.

It was the first human gene underlying a disease that was discovered without first knowing the protein the gene made. The dystrophin gene discovery and the technology that made that discovery possible was developed by Dr. Lou Kunkel and his team at Children's Hospital, Boston with funding from MDA. At the time, the NIH would not fund such research because, as they told Dr. Kunkel, finding a gene underlying a human disease was not possible.

MDA has made a history of doing the impossible. Creating the field of Neuromuscular Disease Medicine, spearheading efforts to discover the first gene in a human disease without knowledge of that gene's protein product, and now opening the frontiers of genetic medicine with some of the first cures and treatments for genetic diseases in the history of medicine.



# MAKING THE IMPOSSIBLE POSSIBLE

MDA's future is focused on the frontiers of genetic medicine and reshaping healthcare in America to improve the lives of patients with muscular dystrophy, ALS, spinal muscular atrophy, and hundreds of other genetic neuromuscular diseases. MDA has in place three well-established complementary programs for doing this that stem from our vision to push the frontiers of genetic medicine and our mission to empower the people we serve to live longer, more independent lives.

## MDA Research

From the very beginning, MDA's founders knew that muscular dystrophy could not be diagnosed properly or cured without new knowledge. Knowledge that could only come from research. That remains true today and the entire field of Neuromuscular Disease Medicine looks to MDA for leadership in this area. Towards that end, MDA's 2022 Clinical and Scientific Conference drew more than 1700 scientists and clinicians from 14 countries to share research progress – the biggest and most comprehensive conference of its kind in the world.

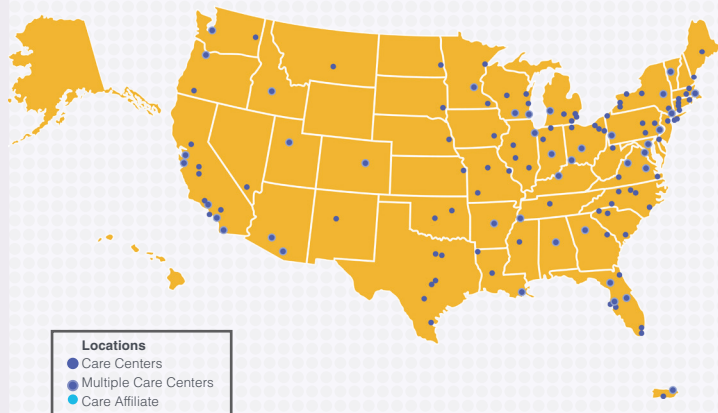
## MDA Advocacy

The ACT for ALS bill signed into law in December 2021 was the largest expansion of government funding for expanding access

to investigational therapies in history. In the signing ceremony, President Biden recognized MDA as a major player in helping get this bill through Congress. MDA advocacy also extends to the FDA where, in recognition of MDA's leading role in advancing genetic medicine, our team has been invited to participate in helping craft new approaches for moving clinical trials forward in genetic diseases, which number over 7000 affecting millions of Americans.

## MDA Care Center Network and MOVR

MDA's Care Center Network and MOVR are rapidly becoming the starting point for physicians and pharmaceutical companies to launch new clinical trials for patients with a multitude of genetic neuromuscular diseases. Today there are over 150 MDA centers serving more than 60,000 patients annually with the latest and most advanced diagnostic and therapeutic approaches for neuromuscular disease. MDA also established a registry program, called MOVR, that collects physician-input on a patient's diagnosis, treatment, progress, and related data. It has attracted the attention of FDA and several leading pharmaceutical companies for the quality and usefulness of its data.



## New MDA Care Centers

- Arkansas Children's Hospital, Little Rock, AR
- Idaho Physical Medicine & Rehabilitation, Boise, ID
- University of Massachusetts Memorial Medical Center, Duchenne Program, Worcester MA
- University of Utah, Pediatric Neurology, Salt Lake City, UT
- Loma Linda University, Pediatric, Loma Linda, CA
- Massachusetts General Hospital, Boston, MA
- NYU Langone Health, Pediatric, New York, NY
- AdventHealth Orlando, Orlando, FL
- Baylor College of Medicine, Houston, TX
- Dell Children's Medical Center of Central Texas, Austin, TX
- Rapides Regional Medical Center\*, Alexandria, LA
- Helen DeVos Children's Hospital\*, Grand Rapids, MI
- Children's Hospital of Michigan\*, Detroit, MI

# PIPELINE OF PROMISE



## CATALYST

**Funding research breakthroughs** with \$1 billion+ invested, second only to the National Institutes of Health

- MDA awards 18 new Development grants and Idea Awards totaling over \$1.6M
- 153 active grants during 2021 and 35 new grants awarded in the same year representing a funding commitment of over \$45M
- MDA joins ALSA and ALS Finding a Cure to provide funding for research into cell therapy that could slow the progression of ALS



## CARE

**Caring for kids and adults from day one** of diagnosis and throughout their life's journey.

- Virtual Clinical and Scientific Conference held with over 1,200 attendees and 100 speakers
- 13 new institutions receive MDA Care Center designation, adding to our national network of 150+ MDA Care Centers
- MOVR Data Hub has added 25+ new sites in 2021, with a projected total of 62 sites by the end of this year, and enrolled 4,000+ participants (growth of 600+ in 2021)



## CHAMPION

**Empowering families** across America through services, support, and advocacy for access, inclusion, and independence

- MDA Virtual Summer Camp, The Great Escape, provides close to 800 children with a week of custom-created content to fit within the virtual space.
- Inaugural MDA Takes Vegas recaptures MDA's Labor Day prominence with innovative event to raise funds and awareness for neuromuscular disease
- MDA, I AM ALS, and The ALS Association Call on Congress to quickly pass ACT for ALS



## COMMUNITY

**Engaging our community** outreach by creating new connections, fostering established relationships, and deepening MDAs impact with its community.

- Quest Podcast launches, featuring conversations on issues facing people with disabilities
- Muscular Dystrophy Awareness Month where MDA shared a “My Powerful Story” series featuring stories from our community
- National Disability Employment Awareness Month highlights the DEI Coalition to facilitate people with disabilities entering the workforce and initiates the STEM Connections program to provide you and young adults interested in science, technology, and engineering, mentoring from professionals in the field

## MDA & IAFF: LEADING THE WAY TOGETHER

When our incredible partnership began 68 years ago, no one imagined how much impact our work together would have on the futures of MDA families, local communities, and the entire neuromuscular disease community. Throughout the years, fire fighters became part of the MDA family and, simultaneously, were side by side with families as they grew older and more independent. Because of the IAFF's dedicated investment, many Locals in the U.S. have their own MDA ambassador story. A story of being together, side by side, for years.

Since 1954, the IAFF has raised over \$690 million through Fill the Boot and other annual fundraising campaigns that support MDA's mission. In 2022 alone, fire fighters raised almost \$12M, and for that we extend our most sincere gratitude. This support enabled MDA to bring two additional treatments to market, provide an in-person and virtual summer camp experience to over 700 kids, and added 13 new Care Center institutions to our network, providing families with the highest quality care from the best doctors in the country.

While the sheer amount of money raised is a cause for celebration, what your contributions have created is the real story. Since our partnership started, the money you have raised has supported MDA in accelerating research, advancing care, and advocating for our families.

Thank you, IAFF! Your partnership has led to the impact of improving and saving lives - just look at what the Domalski family has to say about how their daughter Celine's life has been improved.



Meet the Domalski Family. Amber-Joi, Tom, and C  line live in Philadelphia. After a routine check-up and an eventual visit to the MDA Care Center at Children's Hospital of Philadelphia, C  line was diagnosed with SMA.

"C  line is achieving milestones that we never thought possible and we are over the moon with the outcomes we are seeing."  
The Domalski Family



**MEET THE  
DOMALSKI  
FAMILY**

## → MISSION MEETS IMPACT

### Fill the Boot

Fire fighters across the country have collected critical funds in the community – one dollar at a time – as part of the Fill the Boot program to raise money for MDA. The partnership between MDA and the IAFF began in 1954 when the IAFF signed a proclamation designating MDA as its charity of choice, vowing to continue raising awareness and funds to ensure effective treatments and therapies are found. The dollars raised through Fill the Boot fund MDA's mission of empowering people living with neuromuscular disease to live longer, more independent lives.



### In 2022

**68 YEARS**

celebrated  
as partners

**\$13,885**

averaged per  
Local

**\$11.9M**

raised by  
members

**857 LOCALS**

participated in  
Fill the Boot events

### IAFF + MDA Summer Camp

In 2022, we were thrilled to build back our in-person camp program and continue to provide virtual programming as well. We know many campers and volunteers are ecstatic to be back together in-person at camp while other members of the MDA community enjoyed virtual camp. We're happy that we can meet families where they are and provide that MDA Summer Camp feeling!

MDA was grateful to have 12 IAFF members as MDA Summer Camp Counselors this year.



### TOP 10 Locals\*

1. \$272,141 L2068 Fairfax County VA
2. \$189,279 L0493 Phoenix AZ
3. \$134,361 L0022 Philadelphia PA
4. \$127,637 L0936 Corpus Christi TX
5. \$123,674 L1285 Las Vegas NV
6. \$121,350 L0157 Oklahoma City OK
7. \$117,051 L0624 San Antonio TX
8. \$116,403 L0002 Chicago IL
9. \$115,056 L0176 Tulsa OK
10. \$115,010 L2546 Suncoast FL

### TOP 10 Locals per capita\*

1. \$2,337/member L0226 Marinette WI
2. \$2,025/member L3464 Ontario OR
3. \$1,569/member L1859 Alpena Township MI
4. \$1,502/member L4099 Tahlequah OK
5. \$1,463/member L4333 Stevens County WA
6. \$1,370/member L3429 Lewistown MT
7. \$1,340/member L4384 Hobbs NM
8. \$1,304/member L1935 Coon Rapids MN
9. \$1,252/member L4765 Pueblo West CO
10. \$1,240/member F0116 Vandenberg CA

\*as of 12/31/2022

# MISSION MEETS IMPACT



## MEET JOSE

Jose and his family have been active in the MDA community for years, participating in a variety of fundraisers and activities, most recently the MDA's Muscle Walk of Massachusetts held this past September in Boston Common. Jose's mom, Stephanie, values their connection with MDA for the sense of community and support that it provides.

"Our favorite part of Muscle Walk is always the ceremony that is done in the beginning. It is so amazing to hear about all the amazing work that people have done to raise money. And we love seeing other families just like ours."

Jose's dreams of a Magic Wheelchair costume were brought to life this year when the [MDA Tribute Tour came to Boston](#). It was the perfect opportunity to celebrate the IAFF program and for MDA to come together again with Magic Wheelchair, to collaborate and create an accessible, empowering firetruck costume for one special family.

"I picked a firetruck costume because I always wanted to be a fireman when I grew up and drive the firetruck"  
Jose



Carter Rhodes of North Fort Myers, Florida, had just about the best ninth birthday ever when he received a one-of-a-kind present — a Ghostbusters-themed costume fitted to a new wheelchair. In fall 2021, Carter's name was drawn as the winner of the Halloween Holiday

Joy Instagram contest launched by MDA in collaboration with Magic Wheelchair, a nonprofit that creates fun costumes for kids and adults in wheelchairs.

The day was even more special because of Carter's family ties to IAFF and MDA. His great-grandfather on his mother's side was a fire captain and a liaison for fundraising with MDA before he retired. He helped organize events such as Fill the Boot.



## MEET CARTER

## IN YOUR COMMUNITY

We believe in the power of community and our approach aims for impacts greater than the sum of its parts. Our community efforts focus on having a positive impact on the people we seek to support, fostering unity through engagement with families, volunteers, local institutions, and organizational partners.


## WORKING TOGETHER




## JOIN THE COMMUNITY

 Instagram: @mdaorg

 Facebook: MDAorg

 LinkedIn: Muscular  
Dystrophy Association

 Twitter: @MDAorg

 Advocacy Twitter: @MDA\_Advocacy

 YouTube: YouTube.com/MDA

 TikTok: @mdaorg

 Twitch: MDA\_LetsPlay

 Discord: MDA Let's Play

For a plain text version of this infographic, [please click here](#).

STRENGTH IN UNITY  
STRENGTH IN COMMUNITY



**Dr. Donald Wood**  
*Dr. Wood received an MDA Research Grant nearly 50 years ago and has returned to MDA as President and CEO*



**Meet Ashleigh**  
*Ashleigh is a Specialist in the MDA Resource Center, living with LGMD*



**Meet Justin**  
*MDA National Ambassador Alumni and MDA Advocate, living with CMD*



**Meet Mindy**  
*MDA announces Mindy as its new Quest Editor-In-Chief, living with SMA*



**Meet Amy**  
*MDA National Ambassador*



**250+**  
MDA IS GROWING AND BRINGING BACK TALENT FROM MISSION TO FUNDRAISING



**\$1B**  
INVESTED IN RESEARCH SINCE 1950



**10,000+**  
INQUIRIES INTO OUR RESOURCE CENTER ANNUALLY



**150+**  
MDA CARE CENTERS IN OUR NATIONAL NETWORK



**25+**  
NEW MOVR SITE REGISTRATIONS



**20,000**  
MDA ADVOCATES



**170,000+**  
FOLLOWERS ON OUR SOCIAL CHANNELS



**300,000**  
MEMBERS OF THE QUEST ADAPTIVE LIFESTYLE PLATFORM



**170,000+**  
EMAIL NEWSLETTER RECIPIENTS MONTHLY



**800+**  
VIRTUAL MDA SUMMER CAMPERS

# BOARD OF DIRECTORS

MDA's Board of Directors is comprised of renowned researchers, clinicians, entrepreneurs, business leaders, disability advocates and philanthropists. Together, they constitute a panel of advisors that provides unparalleled wisdom, experience, expertise and commitment. They are an incomparable body of experts who work to make MDA the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases.

## Members of the Board

Steve Farella  
Chairman

*Former Chairman of MDC Media Partners*

Member of the Executive Committee of the Board

Governor Brad Henry  
Vice Chairman

*26th Governor of Oklahoma*

Member of the Executive Committee of the Board

Donald S. Wood, PhD

*President & CEO of the Muscular Dystrophy Association*

Member of the Executive Committee of the Board

Anjan Aralihalli

*Venture Partner, CTI Life Sciences*

John R. Costantino, Esq.

*Managing General Partner, NGN Capital, LLC (Ret.)*

Member of the Executive Committee of the Board

Benjamin Cumbo, III

*Former Government Executive (Ret.)*

Dan Fries

*Senior Vice President, Managing Director, Segal*

Ankur Ghia

*Senior Partner, McKinsey & Company*

Jennifer Gottlieb

*Global President at Real Chemistry*

John Howell

*President & Co-founder, ComSovereign Holding*

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*Former Non-Profit CEO (Ret.)*

Member of the Executive Committee of the Board

Louis Kunkel, Ph.D.

*Professor of Pediatrics and Genetics, Program in Genomics, Children's Hospital Boston*

Member of the Executive Committee of the Board

Elizabeth McNally, MD, Ph.D.

*Professor, Department of Biochemistry & Genetics, Northwestern University*

Hon. Robert Pipia

*Judge, Nassau County District Court*

Member of the Executive Committee of the Board

Matt Plummer

*Designer, Matt Plummer Designs*

Christopher Rosa

*President & CEO of The Viscardi Center*

Charles D. Schoor, Esq.

*Former Law Firm Partner (Ret.)*

Member of the Executive Committee of the Board

Mark Smith

*Chief Financial Officer and Corporate Secretary, Guidon Energy*

Member of the Executive Committee of the Board

Eugene Williams

*Chairman and CEO at ProMIST™ Neurosciences, Inc.*

Victor Wright

*Former Partner of Goldman Sachs & Co (Ret.)*

Lilian Wu, PhD

*Former Executive, IBM Global*

## Emeritus Members of the Board

Dr. Stanley Appel

*Co-director of Houston Methodist Neurological Institute, Chair of the Stanley H. Appel Department of Neurology, Peggy and Gary Edwards Distinguished Chair in ALS at Houston Methodist Hospital, and Professor of Neurology at Weill Cornell Medical College*

Bart Connor

*1984 Olympic Gold Medal Gymnast, SEC/ESPN/ABC commentator and Inspirational Speaker*

Dr. R Rodney Howell

*Professor and Chairman of Pediatrics Emeritus at Miller School of Medicine, University of Miami*

Olin Morris

*Former President and General Manager of New York Times Broadcast Group*



**MEET  
CHRIS ROSA**

“ I celebrated my 54th birthday which is remarkable in that it represents three times the length of life that had been predicted for me when I was first diagnosed with muscular dystrophy in 1976. ”

Dr. Chris Rosa,  
Assistant Vice Chancellor for Student Inclusion, City of New York University  
Newly appointed President & CEO, The Viscardi Center

