# 2021 MDA Muscular Dystrophy Association





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## A LETTER FROM MDA'S PRESIDENT & CEO

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 - 15 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 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 your 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,

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**Donald S. Wood, Ph.D.** President and CEO Muscular Dystrophy Association



## 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, apartmentto-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 NMD 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 NMD 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 cause Duchenne muscular dystrophy (DMD) in some cases and Becker muscular dystrophy (BMD) in others. 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 National Institutes of Health (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 NMD 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.



## MDA 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 NMDs. 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 that could only come from research. That remains true today, and the entire field of NMD medicine looks to MDA for leadership in this area. Towards that end, MDA's 2022 Clinical and Scientific Conference drew more than 1,700 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 7,000 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 Care 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.

#### 2021 NEW CARE CENTER NETWORK LOCATIONS

- 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 The ALS Association (ALSA) and ALS Finding a Cure to provide funding for research into cell therapy that could slow the progression of ALS



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)



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

- MDA Virtual Summer Camp, themed The Great Escape, provided 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 NMD
- MDA, I AM ALS, and ALSA call on Congress to quickly pass ACT for ALS



**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 shares 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 youth and young adults interested in science, technology, and engineering, mentoring from professionals in the field

## **IMPROVING LIVES THROUGH ADVOCACY**

MDA's advocacy team relentlessly led efforts to increase access to crucial care and services, speed up the development and availability of vital therapies, and better promote inclusion in everyday life even throughout the COVID-19 pandemic.

#### Historic ACT for ALS

MDA was one of the leading organizations whose efforts successfully resulted in the ACT for ALS being signed into law in December 2021. In addition to funding new research and programs to speed up the development of therapies for all neurodegenerative disease, ACT for ALS was the largest expansion of government funding for expanded drug access in history and allows more people living with ALS to gain access to experimental therapies. In the signing ceremony, President Biden specifically recognized MDA as a major player in helping get this historic bill through Congress.

#### Innovation with the FDA

The FDA requested MDA's advice and expertise on the next generation of innovative and potentially life-saving treatments and cures. MDA staff gave compelling testimony urging the Agency to support efforts that allow regulatory flexibility when reviewing rare disease therapies; innovative clinical trial design and drug approval pathways for rare disease therapies; increased use of patient data and experiences when evaluating drugs; and more resources to review cutting edge gene therapies.

#### Access to Care

MDA successfully led a large coalition made up of numerous organizations in joint campaigns to increase access to and expand newborn screening programs. Thanks to these efforts we celebrated the passage of the Newborn Screening Saves Lives Reauthorization Act in the U.S. House, which would reauthorize and strengthen the newborn screening program.

MDA also led the effort to create specific diagnostic codes for those living with limb-girdle muscular dystrophies (LGMD) and certain LGMD subtypes. These diagnostic codes, which will be implemented in 2022, will have significant benefits to the community, from potentially shortening the diagnosis timeline, to delivering precise medical care, to improving clinical trials and future access to targeted treatments.

In addition, MDA's advocacy team successfully fought to expand tax subsidies to help people afford health insurance, protect insurance access for those with pre-existing conditions, and secure equitable distribution of the COVID-19 vaccines.



## **DISABILITY INCLUSION**

MDA has been there all along, promoting diversity, equity, and inclusion, elevating the conversation of *disability is diversity*. We work to ensure everyone has the same access to personal freedoms and independence to fully participate in all aspects of community life. Our advocacy efforts through the years have provided better access to health care, higher education, disability employment and more accessible travel.

In 2021, MDA led many legislative efforts to ensure the neuromuscular community faces less discrimination and fewer barriers in living their everyday lives, including working with the Department of Transportation and Congress to improve accessibility on airplanes. MDA worked with partner organizations, and together they took on legislative policies that will increase the number people living with NMD in the workforce.

MDA also joined forces with other disability experts and advocates to bridge the gap between people living with disabilities and organizational ability to connect with the largest untapped pipeline of talent. As employers embrace a remote work



environment, they realize that the workplace is now infinitely more accessible to people with disabilities.

Our goals are to: elevate awareness and create an accessible world where every individual can participate in all aspects of community life; promote and deliver opportunities for dialogue that enhances understanding and emphasizes the lived experience of our community; provide education, programming, and resources aimed at overcoming barriers to accessing life's milestones; and collaborate with other thought-leaders to ensure access and inclusion for all.

#### **DEI COALITION**

MDA is committed to leveraging its voice and platforms to promote diversity, equity, and inclusion, elevating the conversation around *disability is diversity*. We will work to ensure individuals living with disability have the same access to personal freedoms and independence. At MDA, we believe unity is strength. Together, let's lead the way to create a more inclusive and accessible world.

#### DISABILITY EMPLOYMENT

In 2021, MDA established a partnership with Inclusively, the technology-centered employment platform for job seekers with disabilities, to help industries overcome challenges and cultivate employment opportunities.

**K** Inclusively recommended that I apply to my current position at MDA. As someone with a neuromuscular disability myself, it is the honor of my lifetime to work at MDA to continue the effort of providing people across the NMD community effective access to healthcare. I do this not only because the work is important, but also because the people here at MDA care about people like me-not just as constituents, but as people. Our hiring practices are just one example of it.

> - Joel Cartner, Director, Access Policy, MDA

## **CLINICAL AND SCIENTIFIC ADVANCEMENTS**

#### **ADVANCEMENTS IN TREATMENTS**

MDA celebrates the FDA approval of new treatments for **three** NMDs: Pompe disease, Duchenne muscular dystrophy, and myasthenia gravis.



#### 2021 MDA Clinicial & Scientific Conference

The MDA Clinical & Scientific Conference was a four-day event in March held in an all-virtual environment, which included scheduled live-broadcast sessions, on-demand videos, virtual networking sessions, exhibits and poster sessions. The conference provided the most engaging and interactive setting that allowed all attendees to participate, network and connect in real-time and on demand to meet their scheduling requirements. The 2021 conference included concurrent sessions focusing on translational and preclinical research, clinical trials, and clinical management in NMD as well as current topics on COVID-19 and the impact on the NMD community. Our commitment to NMD research and clinical care has never been more vital to the protection of the highly vulnerable community of individuals living with NMDs, their caregivers and clinicians who care for our community than right now.

#### First Annual Insights in Research Investor Summit

MDA launched a new forum to bring together the best in early-stage research with parties interested in funding/in licensing programs within the NMD therapeutic category. The inaugural Insights in Research Investor Summit exemplifies MDA's mission and was developed to continue funding advancements in research pivotal to bringing forward new therapies to improve the lives of patients living with NMD. This is the first U.S.-based forum of its type which convened a broad range of research and investment stakeholders focused exclusively on NMD.

Despite the challenges of a virtual meeting I think the conference was very successful. I appreciated the opportunity to be part of it!

**99** 

- MDA Venture Philanthropy Advisory Committee Member

#### 2022 MDA CLINICAL & SCIENTIFIC CONFERENCE

We built on the virtual success from the 2021 MDA Clinical & Scientific Conference which set the stage for our largest-ever, in person and virtual, conference in 2022 that boasted an even greater international presence than in previous years.







<b>1,261</b> registered attendees	<b>140</b> speakers	22 sessions
21 COUNTRIES REPRESENTED	92 Abstracts Submitted	25 EXHIBITORS
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C Thank you for providing a comprehensive platform that was both user friendly and provided sponsors with adequate means of customizing presence. In this time of unsureness and lack of in-person engagement, MDA afforded us the opportunity to educate and support the NMD community in the best way possible.

- MDA Clinical & Scientific Conference Sponsor

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## **MDA CARE CENTERS**

MDA leads the way in caring for people living with muscular dystrophy, ALS, and related neuromuscular diseases, with the largest nationwide network of multidisciplinary MDA Care Centers. At MDA, we are committed to ensuring that the MDA Care Center network operates with a multidisciplinary approach which brings together the expertise of professionals from a wide range of disciplines in one location to provide coordinated, patient-centered care.

Each Care Center offers a team of physicians, nurses, and other healthcare professionals with unique expertise in meeting the ever-changing needs our community. This is considered the gold standard model of care for individuals with complex medical needs.

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.

### **CLINICIANS**

**66** I never thought I'd see, in my lifetime, such a turnabout in outcome and outlook for patients who now have hope and a better quality of life.



- Dr. Claudia A. Chiriboga, MPH MDA Care Center Director Current research focused on Spinal Muscular Atrophy (SMA) clinical trials



Spinraza has helped Faith stay out of the hospital. It has been a game changer. She is just one patient benefiting from MDA funded treatments.

- Faith's mom



**C**eline is achieving milestones that we never though possible and we are over the moon with the outcomes we are seeing. - Cëline's mom

**SCIENTISTS** 

We received funding from MDA and are excited Spinraza has been approved. " Drugs like it will have the greatest impact if administered early before the onset of symptoms.

- Dr. Adrian Krainer

# MDA NATIONAL CARE CENTER NETWORK



## 90,000+ MEDICAL VISITS

CONDUCTED ANNUALLY

## 150+

LOCATIONS IN THE MDA CARE CENTER NETWORK



2,000 {

CLINICIANS AND SCIENTISTS TRAINED SINCE 1950

\$6M+

60,000+

INDIVIDUALS

LIVING WITH NMD RECEIVING CARE

**EACH YEAR** 

MDA CARE CENTER NETWORK INVESTMENT 13



NEW INSTITUTIONS RECEIVING MDA CARE CENTER DESIGNATION



**48** DEDICATED MDA ALS CARE CENTERS

For a plain text version of this infographic, please click here.

## SUPPORT AND SERVICES

We provide an extensive portfolio of programs and services to help guide our families. At MDA, we know that life with a NMD can be a challenging journey requiring a multitude of resources and support relating to education, careers, accessibility, caregiving, transportation, connecting with community, general disease education and more.

The MDA Resource Center is a collective of individuals with personal and professional experience who strive to empower our diverse neuromuscular community with resources supporting a world of independence and possibility. As the first line of interaction between our community and MDA, the Resource Center and supporting teams supply resources and support to the community at every point in their journey, from initial diagnosis through care to planning for end-of-life care and seek out and deploy resources, advice and tactics to our community.

At MDA, we don't want you to navigate your NMD journey alone; we are here to help.

#### Meet Brooke Smith, LMSW, M.Ed.

With nearly 20 years experience in resource navigation, Brooke is among fellow other master's level social workers in the MDA Resource Center who are committed to providing quality, compassionate care.



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#### A LOOK INSIDE

Each MDA Care Center team includes a physician, social worker, physical therapist and Care Center Coordinator. In addition, the following professionals may be members of the care team:

Cardiologist

Dietician/Nutritionist

Endocrinologist

Gastroenterologist

Genetic counselor or Geneticist

Neurologist

#### Neuropsychologist

Occupational Therapist

Orthopedist

Orthotist

Palliative care professional

Physiatrist/PMR

Pulmonologist

Research Coordinator

**Respiratory Therapist** 

Social Work

Speech-Language Pathologist

## **MISSION MEETS IMPACT**

SERVICE WITH A SMILE AND A WAG. JORDAN WITH HIS SERVICE DOG JOLLY.

## RESEARCH

Support for MDA's research enables us to fund teams working toward breakthrough therapies, which may have a life-changing impact on patients. Our model of funding research across many NMDs means findings from one disease often enable progress in others, maximizing the speed at which we can make progress. Each grant impacts NMD research in a different way, from better understanding the underlying mechanisms of a particular disease to uncovering therapeutic targets to building clinical research infrastructure that will expedite clinical trials to providing early career support to promising young researchers.

In 2021 MDA focused research funding in two areas: Development Grants awarded to investigators at the beginning of their careers and who are on the brink of becoming independent investigators, and the MDA Idea Award Program, which funded bold, innovative research ideas that can have an impact in the field of NMD.

66 These grants do two very important things – help grow the next generation of neuromuscular disease investigators and provide seed funding for those creative, hard-to-fund projects that just need a little boost at this early stage.

- Sharon Hesterlee, PhD, Chief Research Officer, MDA

#### NEW

Since 1952, MDA has invested \$122 million in providing early career support to more than 2,200 earlystage scientists and clinicians. The purpose of the Development Grants program is to expand the number of scientists conducting meritorious NMD research in the laboratory of a senior investigator under whose guidance the researcher will be given flexibility to work independently or as part of a collaborative effort.

#### NEXT

MDA created the Idea Award Program, which funds bold, innovative research ideas that can have an impact in the field of NMD. The program provides seed funding for creative, hard-to-fund projects that need a boost at the early stage. These 2021 newly funded projects will aim to advance research discoveries and new therapy development in multiple areas including ALS, DMD, spinal muscular atrophy (SMA), Charcot-Marie-Tooth disease (CMT) and myotonic dystrophy (DM).

#### INVEST

MDA Venture Philanthropy (MVP) is the Muscular Dystrophy Association's drug development program, which operates within MDA's Translational Research program. MVP is exclusively focused on funding the discovery and clinical application of treatments and cures for NMDs. Adapting elements of the venture capital model, the MVP business plan is characterized by an emphasis on measurable results along with deep involvement by its scientific and industry advisers. MVP has invested over \$56M in promising new therapeutics.

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"ROBUST DATA"

"BETTER ACCESS"

"INNOVATIVE"

For a plain text version of this infographic, please click here.

## **MEET OUR COMMUNITY**

Each year, MDA National Ambassadors serve the mission by traveling the nation and telling their personal stories to inspire millions to help MDA through donations or volunteer action. More than 40 ambassadors have met U.S. presidents, appeared on television, been featured in magazines, and have achieved personal and impressive life goals.



MEET ETHAN LYBRAND

MDA NATIONAL AMBASSADOR



Ethan LyBrand, MDA National Ambassador, is an incredible person with a fabulous personality who engaged so many MDA families and brought smiles to our faces during the pandemic. Ethan quickly made a name for himself hitting all of MDA's social channels with his fun and funny campaign, "Joke A Day for MDA," bringing his comedy skills to bear. His campaign was global and gained national acclaim and recognition with his Shorty Award win and being named one of Newsweek's "Heroes of the Pandemic."

Staying connected during MDA Virtual Summer Camp, Ethan enjoyed the night activities with MDA Let's Play Game nights! Let's Play made a splash in the gaming world over Labor Day Weekend, where supporters and gamers united for the inaugural Takeover Stream-a-thon, to get in the game for a good cause. It was in Vegas that MDA brought together its legacy with an exciting new gaming platform where everyone can play and participate; gaming is the great equalizer.

Nyheim Hines is a running back for the Indianapolis Colts of the NFL and MDA National Spokesperson. He has been a long-time supporter of MDA through the NFL's My Cause My Cleats campaign and has taken his love for gaming on the field off the field as an avid player among the MDA Let's Play community.

"Raising awareness for the Muscular Dystrophy Association is important to me because I have seen my mother, grandmother and uncle live with a NMD. As I always say – together we fight!"



MEET NYHEIM HINES

MDA NATIONAL SPOKESPERSON

Watch all of Ethan's Joke-A-Day for MDA on MDA's YouTube channel.

## **RECREATION AND CULTIVATION**

#### **MDA Summer Camp for Kids**

Throughout the summer, nearly 800 campers joined MDA Virtual Summer Camp with lots of fun additions to keep campers engaged and connected with daily Cabin Chat video calls, Camp Supply and STEM Connections kits. These kits filled with project necessities and swag were mailed to campers before camp started. All these activities kept the campers engaged and excited. As the pandemic continued, MDA remained committed to providing virtual options for campers to build independence, confidence and foster lifelong relationships.

#### **Programs for Young Adults**

In partnership with General Motors, MDA launched its STEM Connections program. This two-part program started with providing intentional activities during each day of MDA's Virtual Summer Camp that focused on STEM concepts. Each camper designed and built their own car, created a creature with adaptations to live in the wild, made a stylus to work with their cell phone, and engineered a boat to float in the water.

The second aspect of STEM Connections was a mentoring program for young adults who expressed interest in a more intensive learning opportunity. STEM professionals volunteered as mentors for the program, representing fields such as mechanical engineering, medicine, computer science and more. Participants worked with their mentors to complete a project over the course of four weeks. One of the most impactful sessions held was a panel discussion led by STEM professionals living with NMD who shared their journey.

In today's workforce, STEM careers are growing exponentially and more diversity in the field is needed to drive innovation, and this discussion informed and empowered young adults to consider STEM-based careers.

For me, it was an introduction to possible STEM careers, but most importantly, it was encouragement to what can be achieved while coping with the limitations of neuromuscular disease.

- Ella, 19



## COMMUNITY SPOTLIGHT



AUDREY TABOR MISS DALLAS TEEN



MAANAV GUPTA SPORTSCASTER



**LEAH ZELAYA** MOVIE STAR



BILLY ZUREIKAT

66 Thank you so much for providing an environment where my child was able to connect with others whom she can relate to. We truly appreciate all of the hard work that went in to making a very memorable week. As a parent, it warmed my heart seeing my daughter so excited every morning to start the camp activities and join in on the Cabin Time video chats.

- Camper's mom

## **EDUCATION AND INFORMATION**

MDA provides expert curated education programs and information. We are focused on the audience's need, utilizing our community insights to inform all resources shared with individuals, families, clinicians, and professionals. MDA will continue to break down barriers through education and access, including our new series of on-demand programming, MDA Access Workshops, providing necessary resources, in multiple languages, to navigate this journey based on individual need and interest.

Our education and information platform includes a magazine, website landing pages, patient educational guides — covering complex topics like clinical trials and genetics — and a monthly e-newsletter, distributed to all clinicians and researchers in the MDA database, that provides MDA Care Centers and the broader clinician and researcher community with a summary of important updates and events from across the NMD landscape.



#### **PROGRAMMING INCLUDES**

MDA Engage Seminars & Symposia On Demand Programs Grand Rounds Webinars Clinician Industry Update Webinars OneVoice Community Insights Considerations in Case Studies Access Workshops

**Community Education Materials** 

Peer-to-Peer

Family Panels

**Educational Slide Sets** 

Professional Advisory Boards

Resource Guides

**Clinical Trial Finder** 

NEW Neuromuscular Disorders Discussion Group on MedShr

# ACCESS SURVEY

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MDA launched the MDA Access Survey in 2021. The survey was developed to better understand some of the common barriers the NMD community faces, such as access to equipment, therapies, education, employment, and financial independence. With over 2,800 responses, this survey provided valuable insight into the access barriers the neuromuscular community faces.



For a plain text version of this infographic, please click here.

## **QUEST MEDIA**

Quest is a newly expanded and innovative adaptive lifestyle platform - including a magazine, a blog, a podcast, and an e-newsletter - owned and operated by MDA. With the power of this platform, we use our collective voices to raise awareness by having important conversations with experts, thought leaders and our community about topics that matter to them, in the interest of empowering and creating more progress for the community of individuals with disabilities.



#### MEET MINDY HEDERSON

DIRECTOR, QUEST EDITOR-IN-CHIEF MUSCULAR DYSTROPHY ASSOCIATION When I was diagnosed with spinal muscular atrophy (SMA) as an infant, no one would have guessed the very thing that was destined to make my life challenging would also fill my life with purpose. MDA became a partner to me early on. As an MDA State Ambassador, I gave speeches to staff, volunteers, and corporate sponsors about how their support made a difference in my family's and my lives. I learned the power of sharing my story and saying, "Thank you." At MDA Summer Camp, I gained confidence and saw the possibility of independence and the power of community.

Being involved with MDA in my childhood taught me to use my voice to make a difference however I felt I could, which led me to become the motivational speaker and author I am today. Now, in this full-circle moment, I am honored to serve MDA and all of you as Editor-in-Chief of the Quest family of content. My promise is to bring all that life and MDA have given me through the years and give that back to YOU in these pages, on the podcast, in the newsletter, and on the blog — because we have life to live and work to do. Let's get started!

## **QUEST BY THE NUMBERS**







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#### A LOOK INSIDE - QUEST MAGAZINE

This quarterly adaptive lifestyle magazine is intended to empower our community through exploring the multidimensional world of progress, independence, and well-being that informs a blend of scientific information, clinical updates, and relevant insights including personal stories and "life hacks." Our goal is to put a spotlight on the power of community.



## SHOW OF STRENGTH

Leading the way as the #1 Voluntary Health Organization for over 70 years, volunteers are our legacy. At MDA, families are at the heart of our mission, and we couldn't fulfill our mission without our volunteers who work tirelessly to inspire and move communities. Thank you to all volunteers, new and longstanding, because you are making a difference! Strength in unity. Strength in community.



MEET MIKE BUSH

MDA VOLUNTEER

**35 YEARS OF COMMUNITY STRENGTH** 

Mike Bush celebrated 35 years of volunteering for MDA in 2021. What started as a local weatherman hosting the MDA Labor Day Telethon on KSDK-TV has grown into an awe-inspiring legacy of volunteerism. He's the longest-serving,

Emmy award winning, TV anchor now on air in St. Louis where he still finds time to fundraise for MDA families at Muscle Walks, MDA Summer Camp, galas and so much more. Thanks to the support of his team at KSDK-TV, the Show of Strength Telethon on Labor Day weekend remains one of the most valued MDA Labor Day legacies.



#### 20 YEARS OF RAISING AWARENESS

Jaime Zelaya and daughter Leah were both born with a rare motor neuron disease called scapuloperoneal spinal muscular atrophy (SPSMA). After Jaime learned the name of his disease he realized the importance of advocating for those who need representation. He was empowered and guided towards the MDA in the early years of his diagnosis. The Zelaya family pursued their calling and turned to the same resource that helped Jaime develop as a person when he was young. Through MDA their family was connected to other families facing similar hardships and obstacles. Through those relationships, they were able to amplify their voice in advocating for their needs in New York City communities and in our nation's capital. Advocacy has given Leah the confidence to flourish in other aspects of her life including her unique talent for public speaking as an MDA ambassador and as an actor in her debut role in the feature film, "Marry Me," starring Jennifer Lopez and Owen Wilson.



MEET THE ZELAYA FAMILY

MDA VOLUNTEERS

## **OUR PARTNERS IN THE NEWS**

Together with our generous partners we are raising funds and awareness for families with muscular dystrophy and related diseases. Since 1950, MDA has been proud to team up with caring corporations, organizations, and brands that generate tens of millions of dollars each year through creative campaigns, cause marketing, and year-round special events.



mda.org/get-involved/meet-our-partners to learn more



For more than three decades, these events have proven to be some of the most productive ways to raise vital funds for MDA... It's a testament to the generosity of our business partners and communities combined with the strength of our longstanding partnership with MDA.

- Carlos Jordá, CITGO President and CEO 010101

20%







TOTAL RETAIL LOCATIONS IN 2021



GOLF AND GALA EVENTS ARE BACK!

25 EVENTS IN 2021 AND MORE SLATED FOR 2022



DIY EVENTS NEW: THE REAL BILLY Z PIZZA FUNDRAISER

For a plain text version of this infographic, please click here.

# MDA WORKING TOGETHER

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.



#### JOIN THE COMMUNITY

- O Instagram: @mdaorg
- Facebook: MDAorg
- in LinkedIn: Muscular Dystrophy Association
- **Y** Twitter: @MDAorg
- Advocacy Twitter: @MDA\_Advocacy
- ▶ YouTube: YouTube.com/MDA
- TikTok: @mdaorg
  Twitch: MDA\_LetsPlay
  Discord: MDA Let's Play
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## 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



#### Ashleigh

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



#### Justin

MDA National Ambassador Alumni and MDA Advocate, living with CMD



#### Mindy

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



#### Ethan

MDA National Ambassador and MDA Summer Camper, living with DMD



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**\$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

A 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

## **FINANCIAL REPORT**

For the year ended December 31, 2021 *(\$ in Thousands)* <u>Financial Information</u>

#### Assets

Cash, cash equivalents, and investments	\$66,264
Contributions receivables and other assets	5,805
Fixed assets, net	3,496
Total assets	\$75,565

#### Liabilities

Accounts payable and accrued expenses	\$7,559
Research and training grants payable	5,380
Credit facilities outstanding	12,567
Pension and post retirement plan obligations	45,337
Total liabilities	70,843

#### **Net Assets**

Without donor restrictions	981
With donor restrictions	3,741
Total net assets	4,722
Total liabilities and net assets	\$75,565

#### Revenue

Special events, net	\$35,463
Contributions	15,139
Other Revenue	737
Total revenue	51,339

#### **Expenses**

Patient and community services	13,546
Research	7,731
Professional public health education	5,772
Fundraising	22,046
Management and general	3,217
Total expenses	52,312

#### **Other Non-Operating**

Net investment return	6,312
Forgiveness of SBA PPP loan	8,660
Changes in unrecognized benefit plan costs	14,432
Total other gains (losses)	29,404
Change in net assets	\$28,431

33 2021 MDA Annual Report



In 2021, the Muscular Dystrophy Association (MDA) had a strong rebound and pivoted out of the pandemic impact of 2020 and the first half of 2021. Change in Net Assets in 2021 were \$28.4 million versus a loss of \$23.0 million in 2020, resulting from the adverse impact of the Covid-19 pandemic.

Fundraising programs increased \$2.2 million or 5.0% from the prior year, as the country slowly recovered from the impacts of the pandemic. With the underlying fundraising programs showing strong growth in the second half of 2021, MDA is well placed for a strong impactful year in 2022.

MDA continued to invest \$27.0 million in program services, which represented 52% of total expenses, versus 51% in the prior year. Total program services expenditures showed a strong increase in direct program payments.

As part of the pandemic restructuring, MDA streamlined the cost of fundraising by \$7.9 million or 27%, and reduced Management and General expenses by \$1.5 million or 31%.

MDA received \$2.0 million of Payroll Protection Plan (PPP Loan) funding from the Federal Government and received forgiveness of \$8.7 million of PPP Loan funding it received in 2020. Subsequently in February 2022, the Association received full forgiveness of the remaining \$2.0 million PPP Loan.

In 2021, MDA saw a strong positive pivot in financial strength, rebounding from the catastrophic impact from the 2020 pandemic, with a strong cash balance on hand, endowment investment portfolio increase, reduced debt obligations, and a significant reduction in Pension and post retirement plan obligations due to the Plan's portfolio performance and interest rate increases.





## **Executive Leadership**

**President and Chief Executive Officer** Donald S. Wood, Ph.D.

**Chief Research Officer** Sharon Hesterlee, Ph.D.

**Chief Financial Officer** Michael J. Kennedy, MBA, CPA

Chief Strategy Officer Kristine Welker

**VP, General Counsel** Henry Lanman

**VP, Human Resources** Peri Gondim

Senior Director, Leadership & People Development Kim Viquesney

VP, Public Policy & Advocacy Paul Melmeyer

**VP, Healthcare Services** Nora Capocci

**VP, Community Engagement** Alicia Dobosz



## **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, Ph.D. President & CEO of the Muscular Dystrophy Association Member of the Executive Committee of the Board

Anjan Aralihalli Venture Partner, CTI Life Sciences

John 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

Nancy Kindelan 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 ProMIS™ 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



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.

MEET CHRIS ROSA

Dr. Chris Rosa,

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

## **2021 COMMITTEE MEMBERS**

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