



2019 Annual Report





Our time to
shine
MDA
Summer Camp

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MDA
Summer Camp

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The MDA Mission

The Muscular Dystrophy Association (MDA) is committed to transforming the lives of individuals with muscular dystrophy, ALS, and related neuromuscular diseases through innovations in science and innovations in care.

As the largest source of funding for neuromuscular disease research outside of the federal government, MDA has committed more than \$1 billion since our inception in 1950 to accelerate the discovery of treatments and cures. Research we have supported is directly linked to life-changing therapies across multiple neuromuscular diseases. MDA supports the largest network of multidisciplinary clinics providing best-in-class care at more than 150 of the nation's top medical institutions.

Since 1950, MDA has served as the only national patient advocacy group supporting more than 43 neuromuscular diseases and the communities affected by these conditions. make progress.

THE MDA IMPACT

Is transforming the lives of **300,000+** people living with muscular dystrophy, ALS, and related neuromuscular diseases...

70
years of supporting people with neuromuscular disease

43+
Neuromuscular diseases supported by our research

1B
Research Dollars invested

150+
Top Medical Institutions with care centers

60K+
patients treated at MDA Care Centers

2,400
clinical providers

12
Medicines brought to market from 2015 - 2021

3K+
Summer Campers experiencing summer camp free of charge





Innovations in Science

A single breakthrough can lead to a cure, and in 2019 MDA supported 252 research projects worldwide. Our network model means findings from one disease often enable progress in others; maximizing the speed at which we can make progress.

Support for MDA's research enables MDA to fund leading research teams working towards breakthrough therapies which can have a life-changing impact on patients. MDA-funded breakthroughs include drugs for amyotrophic lateral sclerosis (ALS), Duchenne muscular dystrophy (DMD), periodic paralysis, Pompe disease, and spinal muscular atrophy (SMA).

Support also inspires bright young scientists to become future researchers. To ensure the long-term success of neuromuscular research, MDA's Young Scholars program funds the best and brightest young scientists to become future neuromuscular disease researchers. These grants pair exceptional mentors with promising grantees to ensure high-quality training in neuromuscular disease research.

Research

- Since its inception, MDA has invested more than **\$1 billion in neuromuscular disease research** to uncover new treatments and cures.
- MDA had **252 active grants during 2019** representing a funding commitment of more than \$66M.
- **45 new grants** awarded in 2019 represented a funding commitment of more than \$9M (note that these 45 grants and their funding commitment are included in the 252 grants in the sentence above).
- In 2019, MDA **invested more than \$16M** in research projects.
- MDA funds projects throughout the drug development spectrum from the earliest discovery stages to clinical trials.

2019 MDA Clinical & Scientific Conference

In 2019 MDA merged our long-standing Clinical and Scientific conferences into our inaugural combined annual meeting, which leveraged MDA's extensive reach into the scientific, clinical research, and clinical practice communities to bring together the world's leading experts in neuromuscular disease.

As the most comprehensive neuromuscular disease meeting in the United States, our conference represents the full spectrum of scientific researchers, medical professionals, and decision makers. Our focus in 2019 was to leverage the expertise of researchers, clinicians, and allied health professionals to accelerate drug development and advance best practices in care management across more than 40 neuromuscular diseases.

Conference by the numbers:

Attendees: **1157**

Speakers: **136**

Posters: **290**

Sessions: **23**

Scientific sessions: **10**

Clinical sessions offering CME credit: **13**

MOVR

MDA's MOVR Data Hub™ (neuroMuscular ObserVational Research), the first-of-its-kind data technology hub powered by MDA's network of Care Centers, collects, and aggregates clinical, genetic, and patient-reported data to accelerate effective therapies and drug development. MOVR is improving the ability of researchers and healthcare providers to enhance the care and management of individuals living with neuromuscular disease, and to aid in the development of clinical trials for promising new treatments. This large dataset will provide researchers with insights into how drugs and other treatments affect outcomes, how clinical trials could be better designed, and how neuromuscular disease affects people the same or differently. It will also ensure that doctors can quickly identify patients who may benefit from new therapies or who may want to participate in a clinical trial.

Medical Education and Resources

The Medical Education team has partnered with the country's top thought leaders and experts to create a series of educational programs including CME-certified webinars, peer-to-peer educational slide decks, and case studies.





Innovations in Care

Since MDA was founded, life expectancy, and quality of life has vastly improved for individuals with neuromuscular diseases. Children and adults are living longer and growing stronger as a result. This is largely due to the comprehensive care provided to families from a wide variety of health care specialists at MDA Care Centers.

MDA started the care center network in 1953 with a single clinic in New York City. Through more than 70 years of dedicated support and investment, MDA has expanded its efforts from a single clinic to the development of the current Care Center Network—the largest and most geographically diverse network of multi-disciplinary neuromuscular disease clinician experts across the US. MDA supports the largest network of multidisciplinary clinics providing best-in-class care at more than 150 of the nation's top medical institutions.

MDA Care Center teams consist of health care professionals dedicated to guiding individuals and families through the diagnostic process and once a diagnosis of a neuromuscular disease is confirmed, helping them take charge by understanding the options for medical treatment and daily management. Members of MDA's multidisciplinary care teams include neurologists, cardiologists, nutritionists, physical therapists, genetic counselors, nurses, orthopedists, physiatrists, psychiatrists, psychologists, pulmonologists, respiratory therapists, social workers, and speech/language therapists.

Critical Access Point for Treatment and Testing

MDA Care Centers are critical points of access for therapies and diagnostic testing. All MDA Care Centers have access to no-cost genetic testing programs for a number of neuromuscular disorders.

Community Education

MDA has prepared programs and resources to help educate our community about the fundamentals of neuromuscular disease. In 2021, all events will be held virtually to engage with a national community audience and provide a safe venue to participate.

Disease Fact Sheets

These fact sheets provide general information about each disease including signs and symptoms, diagnosis, prognosis, and treatments.

MDA Engage Community Education Seminars

These day-long educational seminars empower individuals and families with knowledge and resources around neuromuscular disease. Information is shared by experts in the field on a variety of topics related to care, research, resources, and more. There also are opportunities to ask questions of presenters. These seminars are category specific.

MDA Engage Disease Specific Symposia

These one-day educational events empower individuals and families with knowledge and resources specific to one diagnosis. Information is provided by experts in the disease-specific field on a variety of topics related to care, research, genetics, and more. There also are opportunities to ask questions of presenters.

Living with NMD Resources

Through partnerships with medical thought leaders, community leaders and disease-specific experts, MDA develops and updates educational resources to help support and address the management of living with neuromuscular diseases. Our team creates materials to support health literacy, mental health, provide information about clinical trials, genetics of NMD, Care Center experience, detailed disease specific resources and emergency cards and supplemental at-home support information. In addition, we translate these materials into Spanish.

Quest

Quest Magazine is MDA's flagship quarterly magazine, the largest publication focused on neuromuscular diseases. Quest strives to educate, inspire, and engage readers with the latest information on neuromuscular disease research, as well as content on health and wellness, mobility, travel, and thriving in everyday life.

Strongly Blog

Our Strongly blog is used to communicate research updates, community-member profiles, significant MDA and partner news, and other timely information to members of the neuromuscular disease community.

MDA's National Resource Center

The MDA National Resource Center provides one-on-one support via phone or email for individuals and families looking for information about the diseases in our program, services, community education events, activities, and more. MDA National Resource staff are available Monday through Friday 9 a.m.-5 p.m. CT and are typically able to answer all questions within 1-2 business days.

MDA Summer Camp

Our MDA Summer Camps are places where, for a week, kids and teenagers with neuromuscular diseases can gain independence and have fun as they learn vital life skills, like building confidence, and learning self-advocacy. Each camp is staffed with dedicated health professionals and trained camp volunteers who meet the medical and physical needs of each camper — all at no cost to families.



MDA Advocacy

MDA is dedicated to advocating for national policies and programs that support families with neuromuscular diseases by accelerating the development of therapies and cures, facilitating early diagnosis and treatment from day one, ensuring access to critical support, and promoting policies that safeguard independence for people living with disabilities. In addition to staff, MDA grassroots advocates make sure lawmakers in Washington, DC hear their voices by taking action online, meeting with lawmakers virtually, engaging with social media, and sharing their stories with key decisionmakers. Together with MDA's network of advocates, families, volunteers, and partners, we ensure that the collective voice of our community is heard on Capitol Hill.

National Ambassadors

MDA's National Ambassador program has been in existence for many years. In the early years of MDA, public awareness and understanding of muscle disease were almost non-existent. MDA put a human face on its mission by calling upon people living with these diseases to serve as ambassadors, telling their personal stories, and helping the community to better understand these rare diseases. As MDA's most visible spokespeople, our National Ambassadors spark media interest, drive donor engagement, and play an essential role in motivating and representing individuals living with neuromuscular disease. They share their authentic personal viewpoint of living life with neuromuscular disease and of MDA's impact on their life.



Volunteers

Volunteers are an important part of MDA's 70+-year history. Our volunteers are tightly woven into MDA's fabric—even during the COVID-19 pandemic. Whether volunteering to support a signature MDA fundraising event, serving on a volunteer committee or group, supporting MDA's Summer Camp program, or working virtually or within their communities, MDA volunteers provide unbridled commitment and dedication to our mission.



Our Partners

We believe great impact cannot be made alone. Together with these partners, we're raising life-changing funds and awareness for families with muscular dystrophy.

Our Elite Partners (one of five categories):



The International Association of Fire Fighters (IAFF)

The partnership between MDA and the International Association of Fire Fighters spans 67 years, beginning in 1954 when the IAFF signed a proclamation designating MDA its charity of choice and vowing to continue raising awareness and funds until cures are found. To date, the partnership fundraising activities include 300,000 fire fighters nationwide and has raised \$672 million over nearly seven decades. As MDA's largest national partner, IAFF members support our lifesaving mission in many ways, including their dedicated involvement in MDA's signature Fill the Boot program. We are grateful to all the devoted IAFF members who go above and beyond the call of duty to help families across the country.



CITGO Petroleum Corp.

CITGO is a refiner, transporter and marketer of transportation fuels, lubricants, petrochemicals, and other industrial products. As MDA's largest corporate sponsor, CITGO raises funds in a variety of ways, including golf events, galas and the iconic MDA Shamrocks fundraising campaign. Since 1986, CITGO employees, and its Marketers have raised more than \$200 million to help find treatments and cures, rally communities, and support families with services like MDA Care Centers, MDA Summer Camps, and support groups.



Harley- Davidson Motor Co.

Since 1980, Harley-Davidson Motor Co. continues its rich relationship with MDA through its values of independence and corporate responsibility and its long-standing commitment to MDA families. The Harley-Davidson family of dealers, customers, employees, suppliers and H.O.G. chapters have raised more than \$100 million for MDA. Each year, riders visit MDA Summer Camps to give side-car rides to the kids and help make their camp experience one to remember.

MDA Fundraising Events

MDA Muscle Walk

MDA Muscle Walk is a life-changing event that strengthens families and communities. Every event includes a 1- to 3.1-mile lap designed for participants of all ages and abilities, including a wheelchair and equipment friendly course. Leading up to the event, participants and teams fundraise to help MDA to fund groundbreaking research for promising treatments and provide families with the highest quality care from the best doctors in the country. Muscle Walk is more than a fundraising walk. It's a powerful experience that forges lifelong connections, celebrates families and the barriers they overcome and turns hope into answers.



MDA Team Momentum

Team Momentum is MDA's endurance training program that empowers individuals of all athletic abilities to train for a half or full marathon while supporting kids and adults with muscular dystrophy, ALS, and related neuromuscular diseases. Participants dedicate their miles, muscles, and personal finish line to supporting the neuromuscular disease community. Team members receive access to a world-class customized training program, experienced coaches, and a committed community of support to keep them inspired. Every mile and every dollar raised along the journey helps MDA fund our mission.

MDA Shamrocks Program

MDA's iconic St. Patrick's Day fundraiser is supported by thousands of retailers in hometowns across America to support kids and adults with muscular dystrophy, ALS, and related neuromuscular diseases. Customers purchase a paper MDA shamrock at checkout for a \$1, \$5, or larger contribution. MDA provides all materials to participating retailers, including the paper shamrocks for customers and employees to put their name on to display after making a donation.

Fill the Boot

For more than 65 years, Fill the Boot has been a strong fire fighter tradition. As MDA's largest national sponsor, the IAFF fuels our mission to transform the lives of people affected by muscular dystrophy, ALS, and related neuromuscular disease.



Your Way for MDA

MDA gives individuals and families the choice and tools to raise money for kids and adults living with muscular dystrophy, ALS, and other neuromuscular diseases in their own ways, from hosting a bake sale to running a 5k. MDA provides the tools to make every fundraiser a success.

Galas

MDA hosts numerous fundraising galas across the country throughout the year.



Leadership
(as of May 2021)

Executive Leadership

President and Chief Executive Officer

Donald S. Wood, PhD

Chief of Staff

Kristine Welker

Executive Vice President & Chief Research Officer

Sharon Hesterlee, PhD

**Executive Vice President, Chief Strategy
Development Officer**

Kathy A. Kauffmann

Executive Vice President, Chief Financial Officer, Treasurer

Michael J. Kennedy, MBA, CPA

Board of Directors

Steve Farella
Chairman

Elizabeth McNally, MD, PhD
Director

Governor Brad Henry
Vice Chairman

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Director

Anjan Aralihalli
Director

Christopher Rosa, PhD
Director

John Costantino
Director

Charles D. Schoor, Esq.
Director

Benjamin Cumbo, III
Director

Mark Smith
Director

Ankur Ghia
Director

John Tognino
Director

Jennifer Gottlieb
Director

Eugene (Gene) Williams
Director

Governor Brad Henry
Director

Victor Wright
Director

John Howell
Director

Lilian Wu, PhD
Director

Louis Kunkel, PhD
Director

Financial Report

For the year ended December 31, 2019 (IN THOUSANDS)

Assets

| | |
|---|-----------------|
| Cash, cash equivalents, and investments | \$67,778 |
| Receivables and other assets | \$11,065 |
| Fixed assets, net | \$2,667 |
| Total assets | \$81,509 |

Liabilities

| | |
|---|-----------------|
| Accounts payable and accrued expenses | \$8,934 |
| Research and training grants payable | \$11,383 |
| Line of credit | \$7,500 |
| Pension and postretirement plan obligations | \$54,405 |
| Total liabilities | \$82,223 |

Net Assets

| | |
|----------------------------|----------------|
| Without donor restrictions | (\$5,967) |
| With donor restrictions | \$5,253 |
| Total net assets | (\$714) |

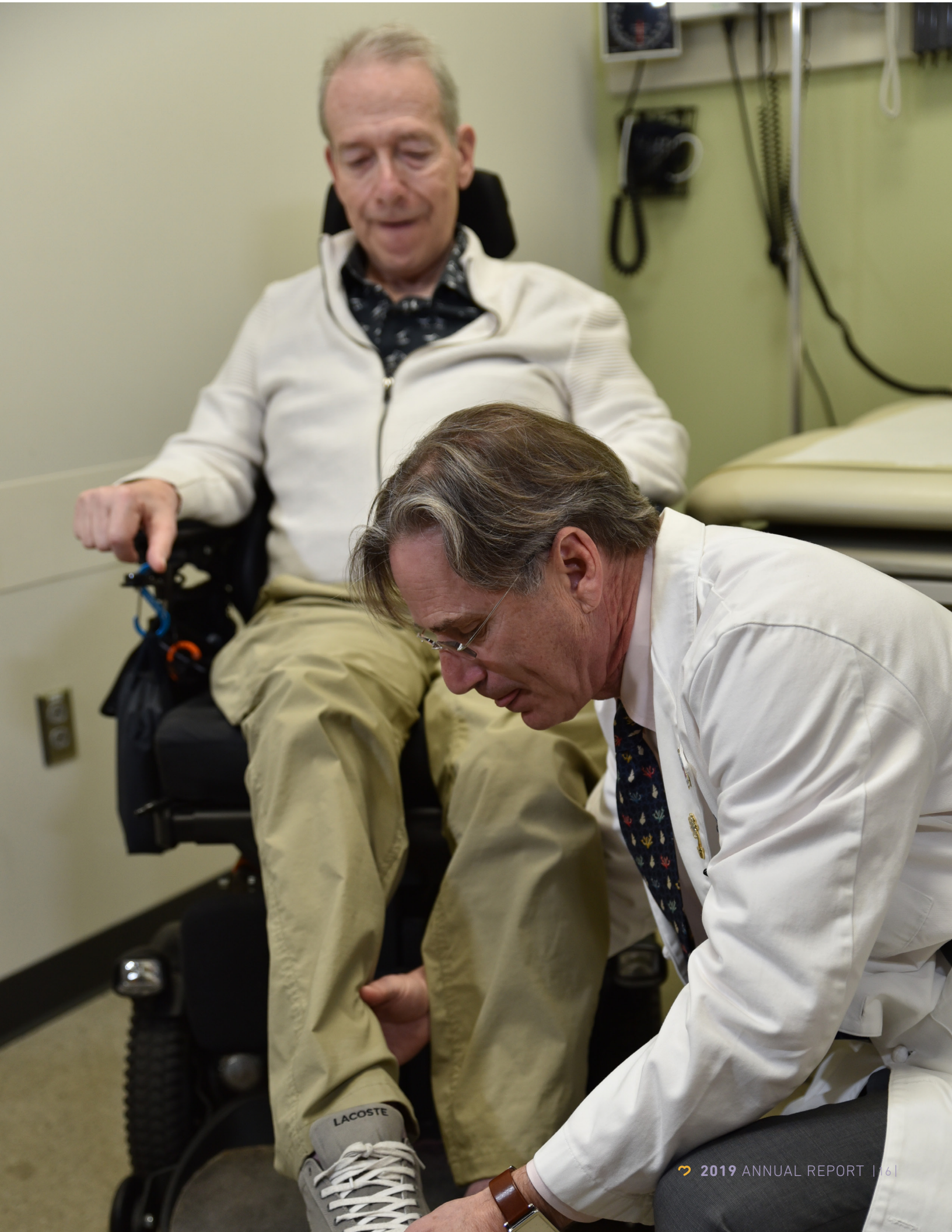
| | |
|---|-----------------|
| Total liabilities and net assets | \$81,509 |
|---|-----------------|

Revenue

| | |
|----------------------|-----------------|
| Special events, net | \$82,805 |
| Contributions | \$14,408 |
| Other Revenue | \$1,062 |
| Total revenue | \$98,275 |

Expenses

| | |
|--------------------------------------|------------------|
| Patient and community services | \$28,615 |
| Research | \$19,856 |
| Professional public health education | \$9,125 |
| Fundraising | \$47,463 |
| General and administrative | \$7,151 |
| Total expenses | \$112,209 |





MDA

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