

2019 Impact Report

THE ALS ASSOCIATION NORTHERN OHIO CHAPTER



CARE



ADVOCACY



RESEARCH



OUR VISION: Create a world without ALS.

OUR MISSION: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

A MESSAGE FROM EXECUTIVE DIRECTOR MARY WILSON WHELLOCK



On behalf of The ALS Association Northern Ohio Chapter, thank you for your generous support of the work that our Chapter provides to those touched by ALS throughout our region. We are pleased to present this Impact Report to illustrate how you've helped.

Commonly referred to as Lou Gehrig's Disease, ALS is a progressive neurodegenerative disorder that causes increased muscle weakness, which leaves patients paralyzed and unable to move, speak, and even breathe – often while the mind is left intact.

For over 30 years, The ALS Association Northern Ohio Chapter has been fulfilling its mission to *discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.* This Impact Report reflects financial contributions and programmatic activity for the fiscal year ending January 31, 2019.

Thanks to our supporters, our Chapter is able to provide critical services for approximately 350 families throughout thirty-three Northern Ohio counties. Our services are provided free of charge – we don't bill for service, and we do not receive any government support. YOU make our work possible! Your generosity provides a wide array of programs including individual support and home visits from our Care Services team, durable medical equipment loans, and loaned communication devices and assistive technology. We also participate in ALS multi-disciplinary clinics and host support groups for patients, caregivers, and the recently bereaved. Our grants to patients offer reimbursement for medically necessary expenses, such as caregiver respite, home health care, travel, medical co-pays, and home modifications. We fully support and fund education and public awareness, advocacy on Capitol Hill, veterans' benefits, and research to find new treatments and a cure.

When I joined the Chapter in April 2011, the ALS landscape had remained relatively unchanged since my mother's journey with the disease ended in June 1999. Then in late July 2014, the largest social media phenomenon ever, the ALS Ice Bucket Challenge, took the world by storm and raised over \$250 million for ALS charities throughout the world, forever changing the landscape of the fight on ALS. The awareness it brought elevated public consciousness about an insidious disease that can affect anyone and the funds raised are advancing ALS research in ways that were unimaginable five years ago, including the discovery of five new ALS genes and the expansion of our clinical care network across the country by 50%.

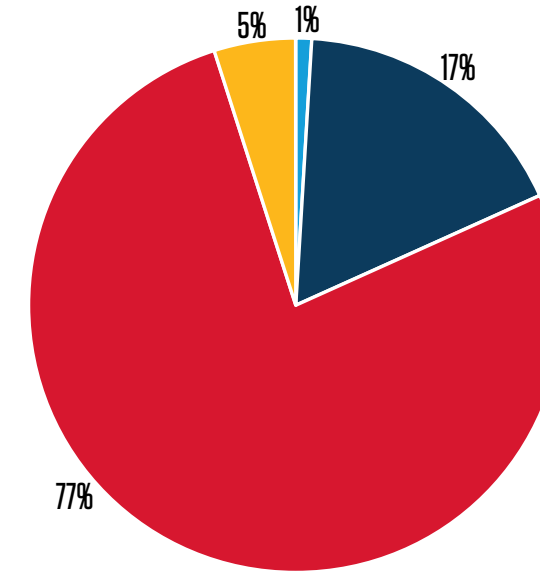
Remember, there is still no identified cause or viable treatment for ALS, so the support of our programs has a direct impact on the lives of those touched by ALS in Northern Ohio.

Read on to learn more about how you've made a difference in the lives of those affected by ALS.

FINANCIALS

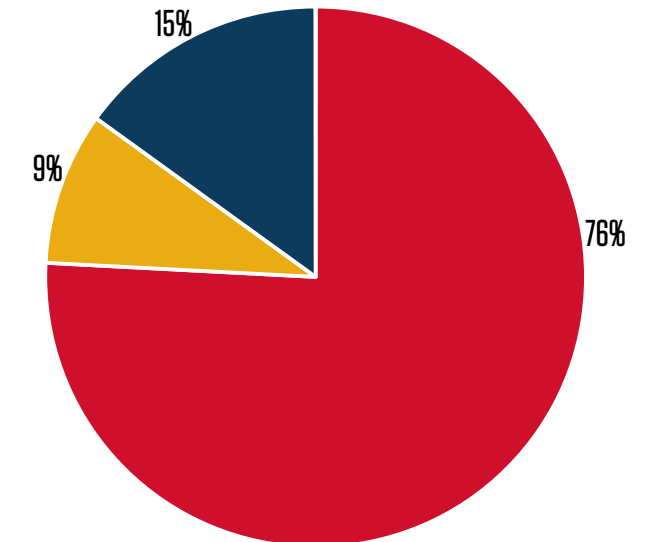
The ALS Association Northern Ohio Chapter does not bill insurance companies or charge any fees for services. All Chapter programs and services are made possible through the generosity of individual giving, foundation grants, corporate sponsorships, special events and state funding. A copy of the Chapter's Form 990 and recent audits can be found at www.alsaohio.org.

REVENUE



- Chapter Events (\$876,301)
- Donations (\$197,396)
- Community Partner Events (\$56,289)
- Grants (\$11,000)

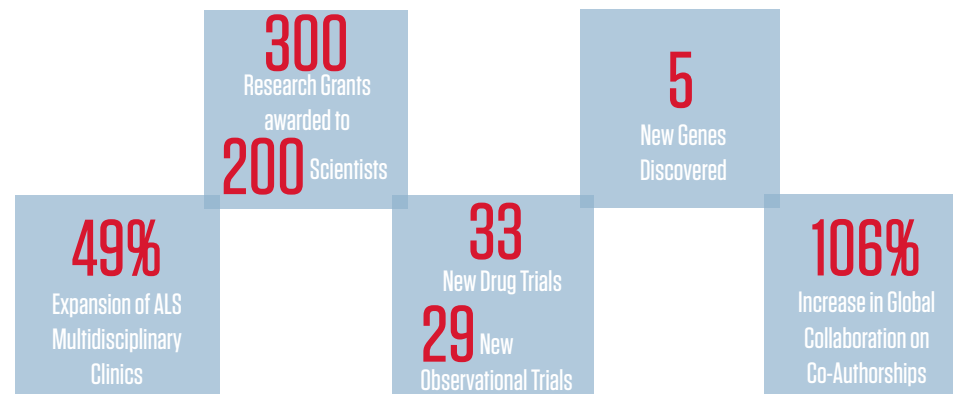
EXPENSES



- Program Services (\$902,875)
- Management and General (\$108,848)
- Fundraising (\$178,935)

* These numbers reflect The ALS Association Northern Ohio Chapter's audited financials as of 1/31/19.

FIVE YEARS OF IMPACT | 2014 - 2019: The ALS Ice Bucket Challenge



www.alsaohio.org

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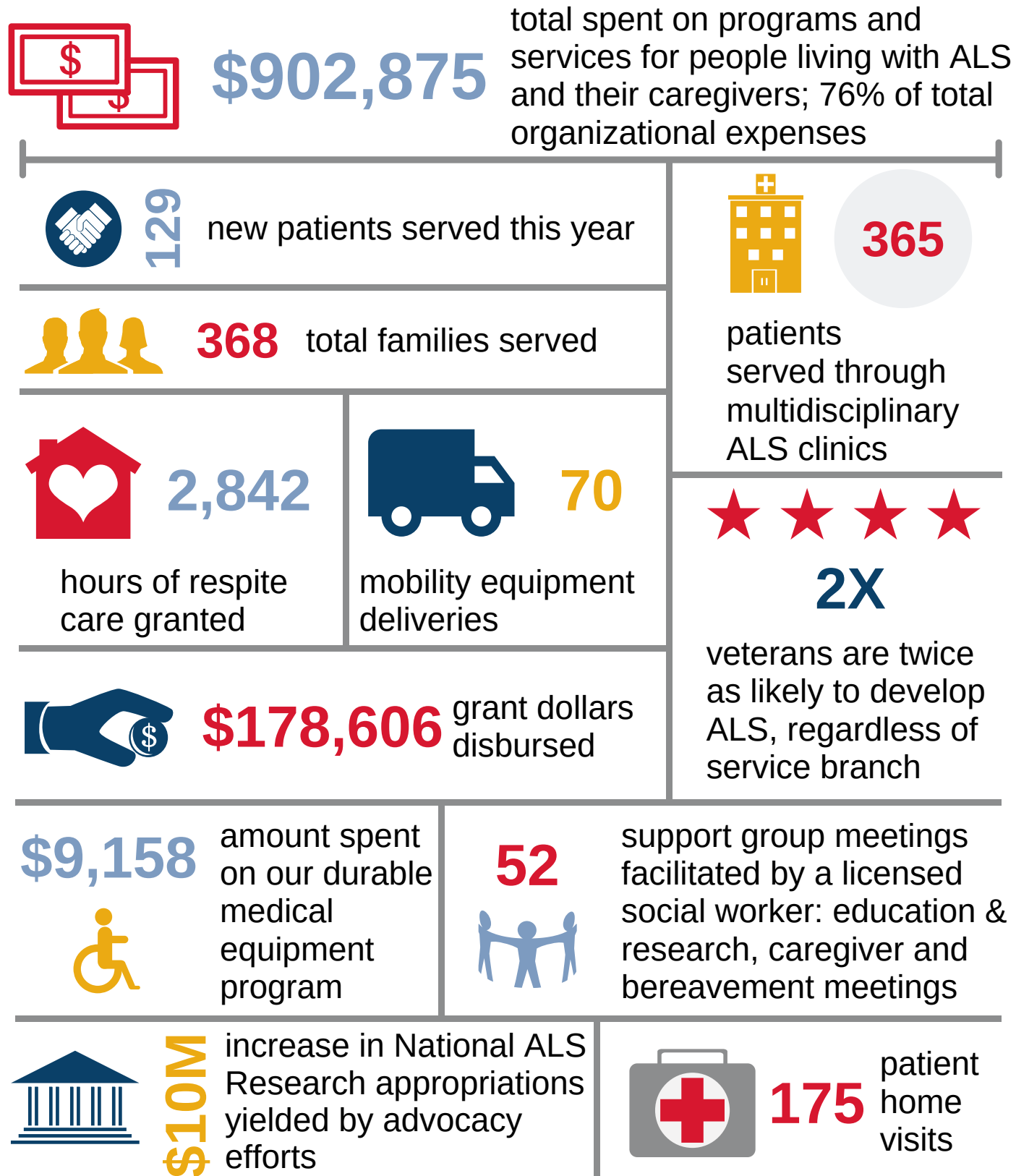
K. James Zinkan
Community Leader

As of 1/31/2020

www.alsaohio.org

People with ALS come first in everything we do.

The ALS Association is dedicated to providing people with ALS, their families and friends with the critical information, support and resources necessary to live a full life and better meet daily challenges. In fiscal year 2018-19, with your support, The ALS Association Northern Ohio Chapter was able to provide the following services.



CHAPTER SERVICES

The Northern Ohio Chapter was founded in 1998 by a group of volunteers to help people with ALS and their families learn more about the disease. The Chapter now serves persons with ALS and their families across 33 counties of Northern Ohio. We are committed to a comprehensive approach to meeting the needs of the ALS community - patients, caregivers, family members, friends and healthcare workers. Thanks to generous community support, all of the following services are provided by the Chapter free of charge:

- Individualized support and home visits
- Medical equipment, assistive technology and communication device loan closet
- Educational & research, bereavement and family & caregiver support groups
- ALS Care Grants
- Founders Respite Care Program
- Education and public awareness
- Advocacy and Research
- Veterans Benefits Assistance

CLINICAL SERVICES

ALS Certified Clinics provide comprehensive care for people diagnosed with ALS using a team of doctors, nurses, therapists and counselors. The Northern Ohio Chapter supports three clinics in our territory that provide comprehensive evaluation and treatment plans for those with ALS.

- ALS Association Certified Center of Excellence at the Cleveland Clinic
- University Hospitals Cleveland Medical Center
- ALS Association Certified Center of Excellence at the Louis Stokes Cleveland Department of Veterans Affairs Medical Center

EDUCATION AND PUBLIC AWARENESS

The Chapter provides educational and research support groups led by Care Service Coordinators, but often include guest speakers on the latest trends in the management of ALS. The groups provide a safe place to discuss questions, problems and the latest information related to ALS care.

Our experienced staff also conducts lectures, publishes a newsletter, maintains a website for information and provides a lending library of books, videos and articles of interest.

ADVOCACY AND RESEARCH

The Chapter believes strongly in the process of advocacy to promote public policy changes to improve funding for ALS specific research, improve standards of care and access to Federal insurance programs. Each year, the Chapter participates in the ALS Advocacy & Public Policy Conference in Washington, D.C. to advocate for continued funding of top ALS-related priorities. The Chapter contributes a portion of its annual funds to support federal advocacy programs and national research. State advocacy programs are also given a priority.



CARE SERVICES
We provide essential assistance for people with ALS and their families at every stage of the disease.

RESEARCH
We direct the most comprehensive ALS research program ever organized - funding over 100 labs across the globe.

ADVOCACY
We tell our ALS stories on Capitol Hill and enact policies that improve the lives of people with ALS and their families nationwide.

\$559,944 RAISED | 2,932 PARTICIPANTS

\$309,390 RAISED | 400 ATTENDEES

Akron Walk to Defeat ALS

\$119,153 Raised

Top Three Teams

Stanley Stampede
Team Steve-O
Team Gretchen

Cleveland Walk to Defeat ALS

\$348,312 Raised

Top Three Teams

RallyWithNatale
Alex's Army
Team Bolzan



Tiffin Walk to Defeat ALS

\$27,529 Raised

Top Three Teams

overcomer
Papa's Pistols
Power of 12

Toledo Walk to Defeat ALS

\$64,950 Raised

Top Three Teams

Charline's Champions
Brooks' Crew
Paul's Crew



The Chapter extends deep gratitude to the families, groups and individuals who organized third party events and activities in fiscal year 2018-19:

100X100 Swim
 Trample ALS Ball
 MZAK Crew 31 Party
 Pizza for a Cause - Team Green
 Kidder Penny War
 John Carroll University Strike Out ALS Day
 ALS Spinathon
 Highway to Health Golf Outing
 Big G Golf Outing
 Bodhi-Fest
 Bud Miller Memorial Event
 Cause an Effect - Team Green
 Team O'Reilly - Angelo's Pizza
 Kelsie Monin Memorial Golf Outing
 Linda Manoloff Memorial Bowling Event
 Brooks' Crew for ALS Golf Outing
 Cruise-In for the Cure
 Johnson Oktoberfest - Cheers to a Cure!
 Alex Massey "At Your Service" Golf Outing
 Jeffrey T. Braden Memorial Golf Outing
 Matt Stanley Marathon

Ride for a Brother
 Guest Bartending - Sonny's Hero
 Team O'Reilly - West Park Station Fundraiser
 The Shelly Co. Shalersville Wildlife Site 5K/Fishing Derby
 Beers to Beat ALS
 Press Grill Charity Golf Outing
 Melt Bar and Grilled Fundraiser
 Come Help Defeat ALS!
 Charline's Champions Golf Outing
 The Big Hat Birthday
 Ales for ALS Pint Night
 Chili Cook Off
 Cleveland Beer Week at Rozi's, Deagans, and Buckeye Beer Engine
 Together We DANCE to Cure ALS
 Browns Sunday Funday with Team O'Reilly
 Dave Calabrese Football Blitz
 Westlake High School Leadership Challenge
 Santa Sleighs ALS!



Alex Massey "At Your Service" Golf Outing



Team O'Reilly - Angelo's Pizza event



Trample ALS Ball

Community Partner Events offer businesses, organizations and individuals an opportunity to increase their recognition and outreach. These events support our programs and services such as the Durable Medical Equipment Loan Closet, the Founders Respite Care Program and Care Grant Reimbursement Program, to name a few.

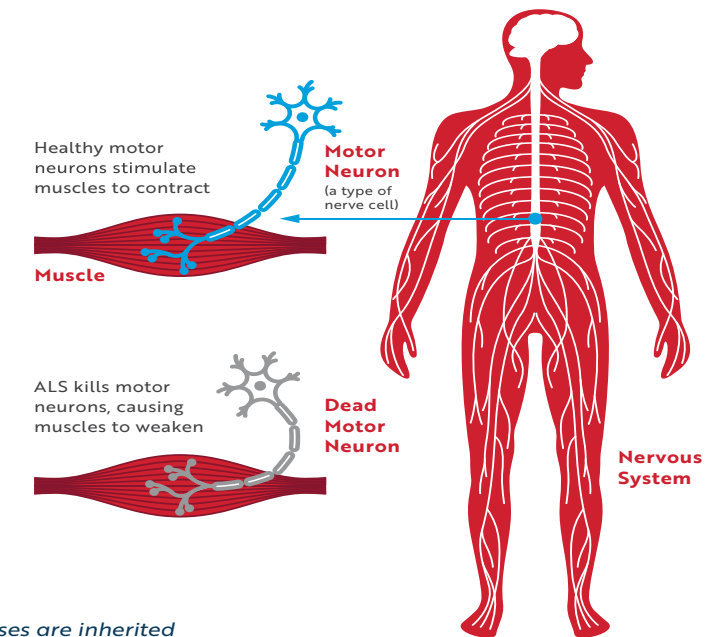
The Northern Ohio Chapter will assist your event with promotion and advertising, including features on our website, online calendar and social media. We can also supply literature and awareness materials.

Please contact our Director of Events and Marketing, John Coyne, at 216-867-1270 or john@alsohio.org to discuss your event.

ALS IS A PROGRESSIVE NEURODEGENERATIVE DISEASE THAT AFFECTS NERVE CELLS IN THE BRAIN AND SPINAL CORD.

ALS usually strikes people between the ages of 40 and 70, and approximately 20,000 people in the U.S. have the disease at any given time.

Although there is not yet a cure or treatment that halts ALS, scientists we fund through our global research program have made significant progress in understanding what causes ALS. But their work is not done. Together, we work toward a cure.



FACTS ABOUT ALS

100,000 people are diagnosed per year

10% 10% of cases are inherited through a mutated gene

2-5 YEARS is the average life expectancy

90% of cases occur without family history

Every **90 MINUTES** someone is diagnosed and someone passes away

\$250,000 is the estimated out-of-pocket cost for caring for a person with ALS

3 Only **4 DRUGS** are currently approved by the U.S. FDA to treat ALS (Riluzole, Nuedexta, Radicava, and Tigtutik)

\$2 BILLION is the estimated cost to develop a drug to slow or stop the progression of ALS

There is **NO CURE** for ALS

You can help change the facts by donating to The ALS Association.

SYMPTOMS

Progressive loss of muscle control

ALS gradually prohibits the ability to:

- Speak
- Swallow
- Walk
- Grasp objects
- Move
- Breathe

DIAGNOSIS

Difficult to diagnose

- ALS is often diagnosed by ruling out other diseases, which may take months or years

MILITARY

Veterans are 2x as likely to get ALS

- ALS affects veterans who served in peacetime and war
- ALS impacts veterans, regardless of the branch of service or the war they served in

The Legacy Society recognizes those who have included The ALS Association in their estate or financial plans through charitable bequests, trusts, insurance, or other forms of deferred giving. We gratefully acknowledge and thank the following members of the Chapter's Legacy Society:

Anonymous
Harriette L. Cochran*
Fred M. DeGrandis
Harry Egner*
Sylvia Feldman*
Bob Feller*
Denise Finkelstein, MD

Jehanna P. Francis
Herbert B. Harris*
Darlene and David Hauserman
Alvin Kendis*
Virginia Kral*
Wayne and Terri Mosley
Donald Patton*

Jay and Lovey Ross
Jill Spencer
Brian and Lynn Toma
Suzanne W. Weber*
Mary Wilson Wheelock
*deceased

For more information, please contact Lynn Iams, Director of Development, at 216-867-1265 or lynn@alsaohio.org.

THANK YOU DONORS

The following is a list of donors who made a gift to the Chapter of \$1,000 or greater between February 1, 2018 and December 20, 2019.

Individual Donors of \$1,000+

Becky and Joe Allgyre
Anonymous
Stacey and Marc Aronstein
Betty Augsburg
Martha Bauschka
James E. Beardsley
Adam and Stacey Berebitsky
Cathy and Marc Blitz
Mr. and Mrs. Manfred N. Brosee
Sandy Cardarelli
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Mr. and Mrs. David R. Shields
Bradley Singer
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Jill Spencer
Mr. and Mrs. Timothy Spencer
Robert L. Stark
Lucy and Rob Staten
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Dale Stetson
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Stacey A. Sutherland
Jim Teubner
Donna Thomas
Brian and Lynn Toma
Ronald R. Turney*
Paul Weber
Edwin Westrick
Parker Wieland
Martin T. Wymer and Ilene G. Roth
Mr. and Mrs. Brian Zinkan
Gregory Zitkus
*deceased

Organizational Donors/Sponsors of \$1,000+

The ALS Association
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American Legion Post 91
American Legion Frank Bender Post 473
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Ancora
Baker & Hostetler LLP
The Beaver Excavating Company
Berean Fellowship Mennonite Church
Bialosky Cleveland
The Big G Foundation

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Grand Rapids Arts Council
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Gwendolyn Elizabeth
Hudson Community Foundation
Hudson Newcomers Club
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KeyBank Family Wealth
KeyBank Foundation
Kiss My ALS Golf Outing
Kohl's
KPMG
Kvetko Family Foundation
Lake Local School District
The Fred A. Lennon Charitable Trust
LinkedIn Matching Gifts Program
Lubrizol Foundation
Mack Industries, Inc.
Mansour Gavin LPA
Alex Massey At Your Service Memorial Golf Outing
Medical Mutual
The MetroHealth System
The Cameron & Katie Miele Foundation
The Kelsie Monin Memorial Golf Outing
MPB Charitable Foundation
Mitsubishi Tanabe Pharma America
NACCO Industries Inc.
The Andrew J. Natale Family Foundation
National Seating and Mobility
Network For Good
Nissan of North Olmsted LLC

North Coast Container LLC
North Coast Event Services, LLC
North Shore Gastroenterology, Inc.
NuMotion
The O'Brien Foundation
OMH-Healthedge Holdings Inc.
Oriana House, Inc.
Painters & Allied Trades, District Council #6
Parker Hannifin Corp.
Perrino Custom Builders, LLC
PNC Wealth Management
PricewaterhouseCoopers LLP
ProMedica Health System
Quantum Rehab
Rayz Cafe
Tricia L. & Robert G. Risman Family Philanthropic Fund
RSM McGladrey LLP
Marilyn Goske Rudick and Richard A. Rudick Family Fund
Ralph and Lucille Schey Foundation
Shelly & Sands Co.
The Shelly Company
The Sherwin-Williams Company
Snavelly Building Company
The Snavelly Group
Soleo Health Holdings, Inc.
Stephenson Family Foundation
Douglas W. Stout Memorial Fund
Stu Family Trust
Synapse Biomedical, Inc.
Tee It Up for ALS
Therma-Tru
Total Quality Logistics, LLC
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United Transportation Union Insurance Association
Vedda Printing
VNA Ohio
James and Shannon Warder Charitable Trust
Westfield Group
Westlake City Schools

Every effort has been made to ensure the accuracy of this list, however, if you have any questions, concerns, or corrections, please contact Lynn Iams at 216-867-1265 or lynn@alsaohio.org.

THE ALS ASSOCIATION NORTHERN OHIO CHAPTER STAFF

Mary Wilson Wheelock
Executive Director

Lisa Bruening
Director of Care Services

Cathy Moyer
Director of Operations

Lynn Iams
Director of Development

John Coyne
Director of Events and Marketing

Jessica Weisensell
Events Coordinator

Cassi Veres
Care Services Coordinator

Amber Johnstone
Care Services Coordinator

Katie Price
Administrative Assistant

ALS ASSOCIATION

Northern Ohio Chapter

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LOOKING FORWARD TO 2020



Strike Out! ALS
May 16, 2020
The Global Center for Health Innovation



National ALS Advocacy Conference
May 31 - June 2, 2020
J.W. Marriott Hotel, Washington D.C.



Akron Walk to Defeat ALS
August 23, 2020
Lock 3

Tiffin Walk to Defeat ALS
September 27, 2020
Tiffin University

Cleveland Walk to Defeat ALS
September 13, 2020
Baldwin Wallace University

Toledo Walk to Defeat ALS
October 4, 2020
Promenade Park

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