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.
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. 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

- 300 Research Papers
- 200 Scientists
- 33 New Drug Trials
- 29 New Observational Trials
- 5 New Genes Discovered
- 106% Increase in Global Collaboration on Co-Authorship

Chair
Dave Hauserman
Community Leader

Vice Chair
Wayne Mosley
Peak Management, Inc.

Secretary
Jehanna P. Francis
NACCO Industries, Inc.

Treasurer
Bill Nagel
Huntington National Bank

Past Chair
Jeffrey Kerkay
Huntington National Bank

Directors
Colleen Kerkay
Invacare Corp

Chris Masterson
The Sherwin-Williams Company

Frances McClellan
Louis Stokes Cleveland Veterans Affairs Medical Center

Jennifer Parmentier
Parker Hannifin Corp.

Natalie Partridge
Marcus Thomas

Jackie Pfadt
Savantage Solutions

Jay J. Ross
Community Leader

Matthew Silfe
Cleveland Clinic

Jill Spencer
Community Leader

Brian Toma
Freeman Heyne Financial Advisors

Martin T. Wymer
BakerHostetler LLP

Brian Zinkan
Primeline Industries

Co-Chair Emeritus
Fred DeGrands
Community Leader

K. James Zinkan
Community Leader

www.alsaohio.org

As of 1/31/2020
MISSION IMPACT

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.

<table>
<thead>
<tr>
<th>PROGRAMS &amp; SERVICES</th>
<th>CARE SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td>$902,875 total spent on programs and services for people living with ALS and their caregivers; 76% of total organizational expenses</td>
<td>We provide essential assistance for people with ALS and their families at every stage of the disease.</td>
</tr>
<tr>
<td>129 new patients served this year</td>
<td>We direct the most comprehensive ALS research program ever organized – funding over 100 labs across the globe.</td>
</tr>
<tr>
<td>368 total families served</td>
<td>We tell our ALS stories on Capitol Hill and enact policies that improve the lives of people with ALS and their families nationwide.</td>
</tr>
<tr>
<td>2,842 hours of respite care granted</td>
<td>2X veterans are twice as likely to develop ALS, regardless of service branch</td>
</tr>
<tr>
<td>70 mobility equipment deliveries</td>
<td>$178,606 grant dollars disbursed</td>
</tr>
<tr>
<td>$187,606 amount spent on our durable medical equipment program</td>
<td>$9,158 support group meetings facilitated by a licensed social worker: education &amp; research, caregiver and bereavement meetings</td>
</tr>
<tr>
<td>52 increase in National ALS Research appropriations yielded by advocacy efforts</td>
<td>175 patient home visits</td>
</tr>
</tbody>
</table>

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 lecturers, 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.

www.alsaohio.org
2018 WALK TO DEFEAT ALS

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

www.alsaohio.org

2018 STRIKE OUT! ALS GALA

$559,944 RAISED | 2,932 PARTICIPANTS

$309,390 RAISED | 400 ATTENDEES

20 years
STRIKE OUT! ALS
Gala and Auction
SATURDAY, MAY 19, 2018

www.alsaohio.org
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
- M2AK 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 C Golf Outing
- Bodhi-Fest
- Bud Miller Memorial Event
- Cause an Effect - Team Green
- O’Reilly Livin’ the Dream 31 Party
- Pizza for a Cause - Team Green
- The Shelly Co. Shalersville Wildlife Site 5K/Fishing Derby
- Beers to Beat ALS
- Press Grill Charity Golf Outing
- Melt Bar and Grilled Fundraiser
- Cruise-In for the Cure
- Johnson Oktoberfest - Cheers to a Cure!
- Alex Massey “At Your Service” Golf Outing
- Jeffrey T. Braden Memorial Golf Outing
- Brooks’ Crew for ALS Golf Outing
- Cruise-In for the Cure
- Alex Massey “At Your Service” Golf Outing
- Team O’Reilly - Angelo’s Pizza
- Charter’s Champions Golf Outing
- The Big Hat Birthday
- ALS for ALS Pint Night
- Chili Cook Off
- Cleveland Beer Week at Rozzi’s, Deagans, and Buckeye Beer Engine
- Together We DANCE to Cure ALS
- Browns Sunday Funday with Team O’Reilly
- Grasp object
- Move
- Breathe
- Speak
- Swallow
- Walk
- ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord.

ALS is often diagnosed by ruling out other diseases, which may take months or years. Although there is not yet a cure or treatment that halts ALS, scientists 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

- **ALS** is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord.
- **Symptoms**
  - Difficult to diagnose
  - Veterans are 2x as likely to get ALS
- **Diagnosis**
  - ALS is often diagnosed by ruling out other diseases, which may take months or years
- **Military**
  - Veterans are 2x as likely to get ALS
- **Progressive loss of muscle control**
  - ALS kills motor neurons, causing muscles to weaken
- **Drug Development**
  - There is no cure for ALS
  - 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
- **Nervous System**
  - Motor neurons are the type of nerve cell
  - Motor Neuron
  - Healthy motor neurons cause muscles to contract

### Community Partner Events

- 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.

### What is ALS?

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 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

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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 30, 2019.

**Individual Donors of $1,000+**

- Becky and Joe Alligre
- Anonymous
- Stacey and Marc Aronstein
- Betty Augsburger
- Martha Bauschka
- James B. Beasley
- Adam and Stacey Berebitsky
- James E. Beardsley
- Betty Augsburger
- Stacey and Marc Aronstein
- Anonymous
- http://www.alsaohio.org

**THANK YOU DONORS**

David and Darlene Hauserman
Jehanna P. Francis
Jill Spencer
Brian and Lynn Toma
Mary Wilson Wheelock
deceased

Mr. and Mrs. Brian Zinkan
Mr. and Mrs. Donald W. M. Zinkan
Mr. and Mrs. Ronald M. DeGrandis
Mr. and Mrs. Fred M. DeGrandis

**THE ALS ASSOCIATION NORTHERN OHIO CHAPTER STAFF**

<table>
<thead>
<tr>
<th>Role</th>
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<tbody>
<tr>
<td>Executive Director</td>
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| Director of Development           | Lynne Iams                               |
| Director of Care Services         | Lisa Bruening                            |
| Director of Events and Marketing  | Cassi Veres                              |
| Events Coordinator                | Cassi Veres                              |
| Care Services Coordinator         | Lisa Bruening                            |
| Care Services Coordinator         | Cassi Veres                              |
| Administrative Assistant          | Katie Price                              |
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

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

Tiffin Walk to Defeat ALS
September 27, 2020
Tiffin University

Toledo Walk to Defeat ALS
October 4, 2020
Promenade Park

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