

2020 Impact Report

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.

CHAIR OF THE BOARD, WAYNE MOSLEY



On behalf of the Board of Directors 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.

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

Thanks to our supporters, our Chapter is able to provide critical services for approximately 400 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!

Please note that the financials contained within reflect the fiscal year ending January 31, 2020, our most recent audited financials. Clearly, these numbers reflect pre-pandemic efforts. You can see in our executive director's letter that this year is a much different story, but not nearly as bad as we originally anticipated.

I encourage you to take a few minutes to review this Impact Report to get a better understanding of what your contributions have meant to those living with ALS right here. And I'd like to recognize and thank our chapter's wonderful staff, who have been responsible for delivering the services that you have entrusted them with. They have responded tirelessly to adapt their approaches in this environment without sacrificing quality or timeliness of these services. Having worked closely with other chapters throughout our organization, I can tell you that the Northern Ohio staff is one of the most respected and sought-after in the entire ALS Association. In short, your support could not be in better hands!

As we continue to face this unprecedented pandemic and economic uncertainty, I want to thank you for your generosity in spite of these difficult circumstances. Thank you for helping us to continue to help families navigate their ALS journeys.

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A MESSAGE FROM EXECUTIVE DIRECTOR MARY WILSON WHEELOCK

So much has changed in our world since I last sat down to write the introductory letter for our Impact Report. It was almost exactly a year ago that I was preparing the letter for our 2019 report, and we were on the verge of celebrating our most successful year to date, other than 2014's ALS Ice Bucket Challenge. As Wayne mentioned, this Impact Report features the audited financials from the previous fiscal year, so what you will see on page 13 reflects LAST YEAR. It was an outstanding year!

This year, without saying, is a whole different story. I want to start by saying thank you for making this year way better than we thought it would be. Thanks to you, our Walk to Defeat ALS events have raised nearly 80% of goal. Nonprofit events across the country are seeing 40-50% declines. We are on track to finish this year at nearly 70% of budget, which is much better than the 50-60% we had originally anticipated. It still means that we are facing a loss of nearly \$470,000 in revenue, compared to the fiscal year ending January 31, 2020.

The pandemic has canceled so much in our lives, but ALS is not canceled. Our families can't wait for better treatments and a cure. Thank you for sticking with us during these challenging times, and bringing us hope for tomorrow. Together, we WILL create a world without ALS!



A handwritten signature in black ink that reads "Mary Wheelock". The signature is fluid and cursive.

Mary Wilson Wheelock
Executive Director

THE ALS ASSOCIATION NORTHERN OHIO CHAPTER STAFF

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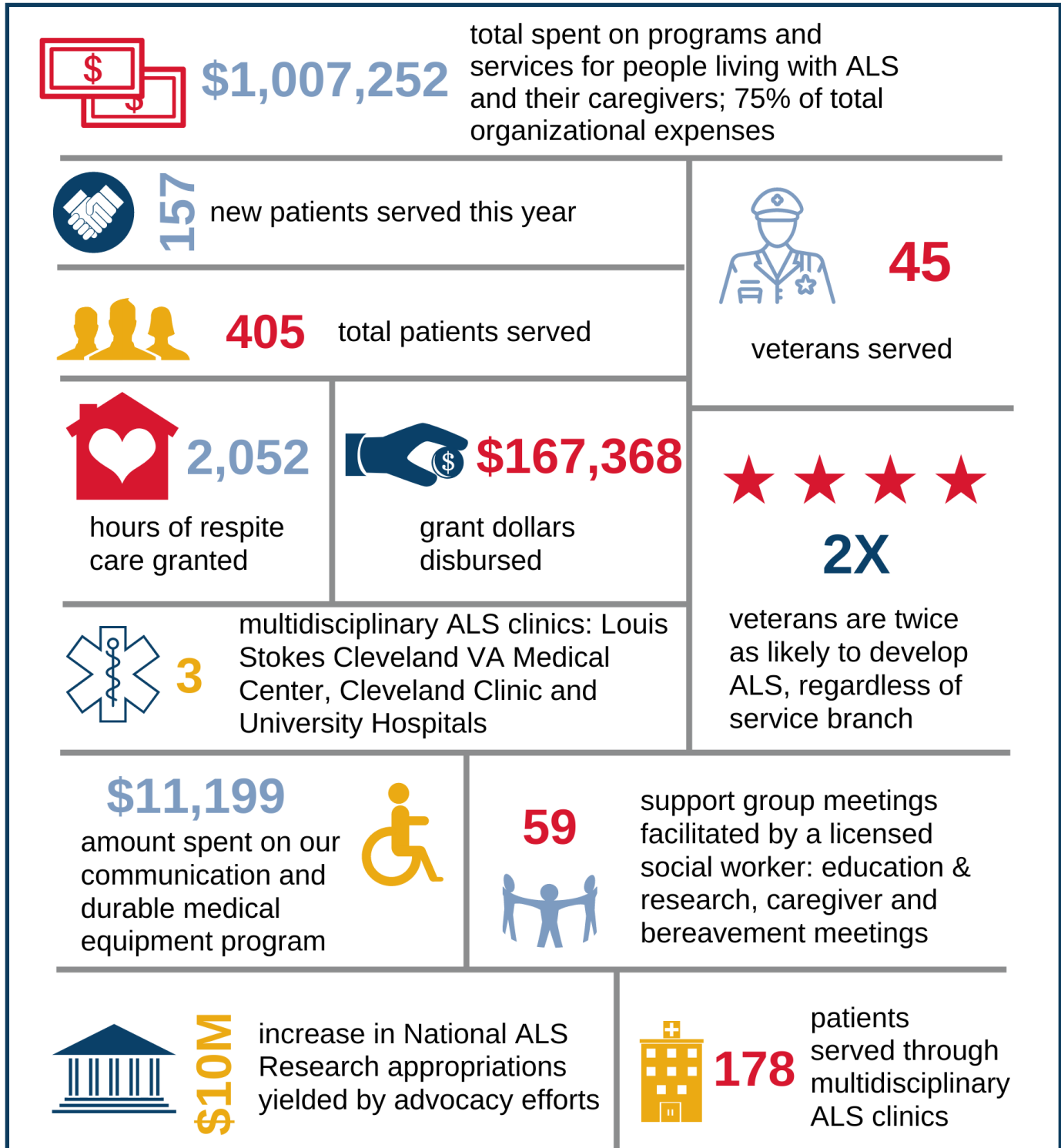
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MISSION IMPACT

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 2019-20, 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 1988 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 and research, bereavement and family and caregiver support groups
- ALS Care Grants
- 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 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.

2020 MINI-WALKS TO DEFEAT ALS

\$435,006 RAISED | 926 PARTICIPANTS

AKRON WALK TO DEFEAT ALS

\$63,193 Raised

TOP THREE TEAMS

Stanley Stampede
Patt's Peeps
Jerry's Jewels

CLEVELAND WALK TO DEFEAT ALS

\$307,347 Raised

TOP THREE TEAMS

Ronnie's Raiders
Willie Strong
Sonny's Hero

TIFFIN WALK TO DEFEAT ALS

\$10,715 Raised

TOP THREE TEAMS

Papa's Pistols
Power of 12
overcomer

TOLEDO WALK TO DEFEAT ALS

\$53,751 Raised

TOP THREE TEAMS

Charline's Champions
Mary Ann's Quilting Bees
Team Scott

This year, the Chapter hosted our very first Mini-Walk to Defeat ALS. Our participants were able to gather in groups based on their comfort level and local guidelines and walk wherever they liked!



We wish to share a note of gratitude for Andrew J. Natale, our honorary chair of the Cleveland Walk to Defeat ALS. Andy was personally responsible for securing over \$100,000 in Walk sponsorships in 2020. His Cleveland team RallyWithNatale continues to be one of the top Cleveland teams. A huge thank you to Andy and his supporters!








2020 RE-IMAGINE STRIKE OUT! ALS



THE NINE INNINGS

Because ALS hasn't been canceled, and people living with ALS need us now more than ever, we forged ahead to Re-Imagine Strike Out! ALS through Nine Innings that recreated many of the most popular aspects of our annual event in a safe (virtual) way.

 The Re-Imagine Strike Out! Facebook Page reached 1,900 people.	
In the weekend of the virtual awards ceremony, we gained 54 social followers. 	The Re-Imagine Strike Out! ALS 2020 fourth inning Facebook Live Awards Ceremony reached 7,765 people and received 5,873 views. 
 The eighth inning featuring Lou Gehrig's Luckiest Man speech reached 21,083 people and received 7,593 views.	
Re-Imagine Strike Out! ALS 2020 raised \$132,443 	

1ST INNING Opening Day April 14

Featured our amazing emcee, Monica Robins, WKYC Senior Health Correspondent, performing the National Anthem.

4TH INNING We went live! May 16

On the day we would have gathered in the Global Center for Health Innovation, we hosted a Facebook Live awards ceremony.

7TH INNING Never Forgotten June 16

Showcasing a beautiful rendition of "God Bless America" performed by Mary Jo O'Regan, we paid tribute to those who lost their battle with ALS in the last year.

2ND INNING Linda and Richard's story April 22

Linda Smith, a person living with ALS, accompanied by her husband, Richard, shared her ALS journey and how your support helps her and her family.

5TH INNING Online Auction May 24 - June 1

Our silent auction, a perennial crowd favorite at the annual Strike Out! ALS gala, was conducted online.

8TH INNING Luckiest Man June 23

Honoring Lou Gehrig, the "Iron Horse of Baseball," Northern Ohioans with ALS and their family members read Gehrig's famous "Luckiest Man" speech.

3RD INNING Online Auction May 3 - 8

The North Coast Woodturners contributed their handiwork to the silent auction as a memorial to their friend, mentor, and master craftsman, Jim Pugh.

6TH INNING Virtual Pledge Drive message June 9

Northern Ohio Chapter board member, Jill Spencer, shared her ALS journey with her husband, Dan, and the named fund she established.

9TH INNING Thank you! June 30

Wrapping up the campaign, we offer our greatest thanks to those who sponsored, participated in, donated to, and shared our event.

COMMUNITY PARTNER EVENTS

The Chapter extends deep gratitude to the families, groups and individuals who organized third party events and activities in 2019 and 2020 (in order of occurrence).

Trample ALS Ball
 Shoot for Shine & ALS
 24 Hour Video Game Streaming
 Run to the Rapids
 Hudson Progressive Dinner
 Tee It Up for ALS
 Loose and Free - Patterns, Lines, Shapes, and Colors: an art exhibit at the Beachwood Community Center
 Kiss My ALS Memorial Golf Outing
 Battle of the Bands
 Angelo's Pizza Fundraiser - Team O'Reilly
 Melt Mondays - Team O'Reilly
 Highway to Health Golf Scramble
 Brooks Crew Golf Outing
 Big G Golf Outing
 Lago Charity Brunch - Team O'Reilly

Rozi's Wine Event with Columbus Brewing
 Kelsie Monin Memorial Golf Outing
 Cause An Affect - Chipotle for Team Green
 Cruise-In for the Cure
 Alex Massey "At Your Service" Golf Outing
 Jeff Braden Memorial Golf Outing
 Spirit Night at Chick-Fil-A
 Hops for Moms Beer Tasting
 The Shelly Co. Shalersville Wildlife Site 5K and Fishing Derby
 Annual Team O'Reilly Fundraiser
 Danny Boy's for Sonny's Hero
 Mike Good Memorial Cup
 Charline's Champions Golf Outing for ALS

James Seminaroti Benefit Golf Outing for ALS
 Craft and Vendor Show
 Adult Hand Turkey Party
 Christmas at Hillside
 Capt. Ron "Cure ALS" 100x100 Swim
 Cleveland Bourbon Co-Op
 Press Grill Charity Golf Outing
 Westlake High School Leadership Challenge
 Principle Business Enterprises Jeans Day
 Bodhi Fest
 MarioThon for ALS
 Steps for Seth 5k
 Hammer ALS
 Friday's Gives Back - ALS
 Cleveland Marathon
 Rea & Associates Walk to Defeat ALS
 Press Grill Charity Golf Outing



Mike Good Memorial Cup



Shoot for Shine ALS



James Seminaroti Benefit Golf Outing

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 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@alsaohio.org to discuss your event.

PATIENT HIGHLIGHT: LINDA SMITH

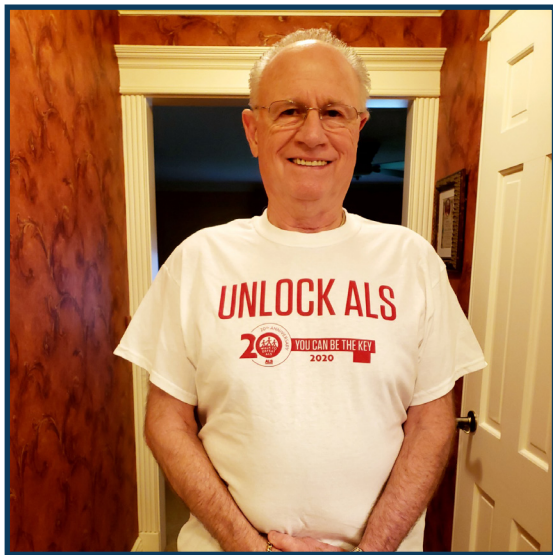


“
The grant program has
been a godsend in
helping with expenses.
- Linda Smith
”

Linda Smith, a person living with ALS in Willard, OH, accompanied by her husband, Richard, shared her ALS journey and how your support helps her and their family.

The ALS Care Grant Program offers up to 50 grants per quarter for up to \$500 per grant. Grants are utilized for services related to patient care, including durable medical equipment purchase/copays, transportation assistance, speech generating device purchases/copays, home modification, and much more.

LEGACY SOCIETY MEMBER HIGHLIGHT



“

It makes me proud to say I'm a part of the organization.

- Jay Ross

”

Jay Ross tells why he and his wife, Lovey, are members of the Legacy Society

When Jay was only 12 years old, his father was diagnosed with ALS. Back in the late 50's and early 60's, ALS did not have the support that it does now. Jay recalls many trips back and forth to the hospital as a child. At first, the hospital claimed his father was suffering from a mental illness. A year later, it became more and more obvious that he was being affected by ALS. Within the following year, his father passed away.

“For a while, it felt like I was too close to the disease,” Jay said, “When I was old enough, I finally accepted the fact that I could handle being on the board and talk about this disease and not have it affect me adversely.”

Jay currently serves on the Governance Committee and the Development Committee on the ALS Association Northern Ohio Chapter's Board of Directors. Prior to this, he served on the Board of Directors for Bellflower for 14 years. He gained a lot of experience as a board member and when he was ready, decided to bring it to the ALS Association.

“You can do a lot of things as a non-board member,” Jay said, “but I felt with my background in business that I could bring something more to the table. Now I feel proud to tell people that I am a member of the board.”

In addition to being on the board, Jay, along with his wife Lovey, are a part of the Legacy Society for The ALS Association. 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. When deciding where to start their legacy, Jay and Lovey confided in their church and priest for a long time before deciding on The ALS Association.

“At our church, we have seen probably 7 or 8 ALS cases in the last 5 years of people we have been close to,” Jay said. “We got to share our passion with the church for finding a way to cure this disease and felt it was the right thing to put it in writing.”

When recalling his time with The ALS Association, Jay reflected fondly on the Ice Bucket Challenge and all of the Walks to Defeat ALS that he and his family and friends could participate in. To this day, Jay and Lovey are proud to be able to raise the money they have for the organization and continue to do so every year.

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:

Char Arthur	Herbert B. Harris*	William Penney
Harriette L. Cochran*	David and Darlene Hauserman	Jay and Laverne Ross
Fred M. DeGrandis	Ruth Hopkins*	Jill Spencer
Harry Egner*	Alvin Kendis*	James E. and Carole A. Studley*
Sylvia Feldman*	Virginia Kral*	Brian and Lynn Toma
Bob Feller*	Wayne and Terri Mosley	Suzanne W. Weber*
Denise Finkelstain, MD	William and Nicole Nagel	Mary Wilson Wheelock
Jehanna P. Francis	Donald Patton*	*deceased

For more information, please contact Lynn Iams, director of development, at 216-236-3607 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, 2019 and November 20, 2020.

Individual Donors of \$1,000+

Becky and Joe Allgyre
 Anonymous (3)
 Marcia Armes
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 Beth Yates
 Mr. and Mrs. Brian Zinkan
 *deceased

Organizational Donors/Sponsors of \$1,000+

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THANK YOU DONORS (CONTINUED FROM PAGE 11)

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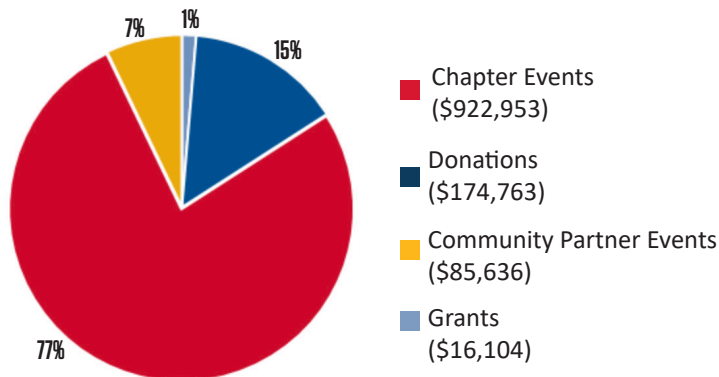
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 Westlake City Schools
 Pat Westrick Foundation

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 216-236-3607 or lynn@alsaohio.org.

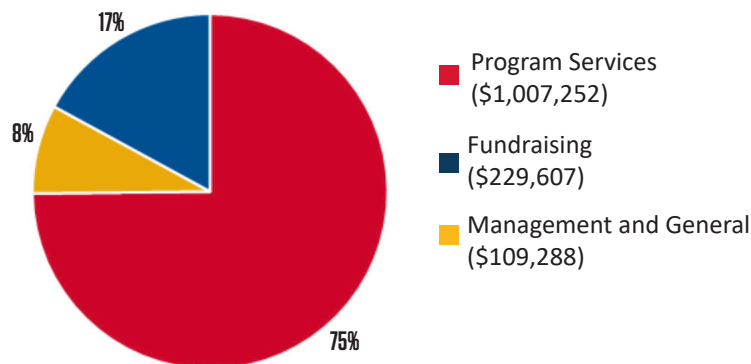
FINANCIALS

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 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



EXPENSES



* These numbers reflect The ALS Association Northern Ohio Chapter's audited financials as of 1/31/20.

PROMISING NEWS IN THE FIELD OF RESEARCH



[The New England Journal of Medicine published encouraging clinical trial results showing that Amylyx Pharmaceuticals' AMX0035 brought statistically significant benefits to people living with ALS.](#) You may have seen the national media coverage of this news and can sense the renewed sense of hope across the ALS community.

Thank you. You made this possible.

The ALS Association was able to make substantial grants to Amylyx Pharmaceuticals and to the clinical trial consortium administering the trials thanks to donation from people like you who participated in, or were moved by, the ALS Ice Bucket Challenge in 2014. You believed in a world without ALS and made a donation that resulted in this promising drug - one we hope will become a treatment option for every person with ALS as soon as possible.

This is your news. And we hope you will share it broadly.

We invite you to learn more about why we can't wait to make this treatment available on the Association's [blog post](#). You can also stream our [podcast](#) or read some of the top national stories covering the AMX0035 trial results.

- [Today Show](#)
- [NBC Nightly News](#)
- [New York Times](#)
- [Wall Street Journal](#)
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- [US News & World Report](#)

We can't wait to find effective treatment and a cure. Thank you for helping us on that journey!

ALS
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