THE YEAR
IN REVIEW

The ALS Association Mid-America Chapter has been fighting on behalf of people living with ALS and their families since its inception in 1978. With over 40 years of experience serving the ALS community, and our partnership with the National ALS Association, we lead the way in research, care services, public education, and public policy by giving help and hope to those facing the disease.

People living with ALS and their families come first in everything we do. We proudly support five ALS-specific multi-disciplinary clinics throughout our three-state service area; and help families navigate challenges presented to them at every turn by this complex and devastating disease. Our care services staff members walk with our families every step of the way and are a shoulder for them to lean on. The continuation of these essential services relies on the donations of generous supporters, unwavering volunteers and dedicated staff.

2019 was a record breaking year: the number of clients we served and dollars we raised. We look forward to 2020 with a sense of urgency. Now is our time to defeat ALS.

Colleen E. Wachter
Executive Director

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.
As The Mid-America Chapter sprints into our fifth decade of work, we pause to examine the financial hardships our families face. ALS is an expensive disease, and often family caregivers are forced to leave their job to provide care to their loved one.

“The grant helped our family with extra expenses related to Chad’s disease”

- Sarah Liebl
What started in the livingroom of Keith and Sue Worthington in 1978 has now grown to a three-state Chapter with offices in Kansas City, Omaha, Springfield and Wichita. The Chapter supports five ALS-specific multi-disciplinary care clinics, hosts 10 Walks to Defeat ALS and provides help and hope to hundreds of families every year. The Mid-America Chapter is a guiding light for families battling ALS throughout America’s heartland.
TO OUR SUPPORTERS:

THANK YOU

THE TRUST YOU PUT IN US

Until all people living with ALS have access to high-quality care, effective treatments, and eventually a cure, we must continue to pursue more research, more funding, and a better quality of life for people living with this devastating disease. The Mid-America Chapter is committed to financial transparency and will work tirelessly to ensure that your donation will be used to make the greatest impact for those living with ALS and their families.

OUR DONORS

$100,000 and Above
Anonymous

$25,000 and Above
The Estate of Betty Conrad
Constance M. Cooper Charitable Foundation
Downing Family Foundation
Davis Bethune & Jones
Miles & Emery Golson
Ken & Jan Shannon

$10,000 and Above
Anonymous • Gilbert & Joanna Adams • Avaya • Jane Bennett
• Blue Cross and Blue Shield of Kansas City • CoxHealth • Dr. C.C. and Mabel L. Criss Memorial Foundation • Jay & Lyn Daugherty • GEHA • Kyle Hoffman • Lewis H. Humphreys Charitable Trust • Jacobson Holdings • Robert W. & Mary Jo Loyd • Mann Family Foundation • Russ and Helen Meyer Charitable Trust • Murphy-Hoffman Company • Tim & Elin Murphy • Debra Parr • TECH Inc. • Tito’s Handmade Vodka • UMB Bank
OUR LEADERSHIP
The heart of the organization

“What is the essence of life? To serve others and to do good.”
~Aristotle

OFFICERS OF THE BOARD

Chris Tonniges
President

Suzie Apel
Vice President

Jason Leiker
Secretary

David Watkins
Treasurer

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John Bennett
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Bill Perry
Brooke Runion
Ross Simpson
Steven St. John
Greg Steinberg
Pete Story
Chris Wilson
David Wurth
The following unaudited summary reflects Chapter-wide financial activity for the year that ended January 31, 2020.

### Income

- **Individual Gifts**: $711,473
- **Grants**: $39,354
- **Special Events**: $330,105
- **The Walk to Defeat ALS**: $1,325,622

### Expenses

- **Program**: 83%
- **Administrative**: 9%
- **Fundraising**: 8%
PROVIDING ASSISTANCE
One Family at a Time

NEWLY DIAGNOSED
Information from our care services team and trusted outside sources are customized to the needs of a person diagnosed with ALS.

CONSULTATIONS
Our Care Services team includes professionals who are available to assist with many needs.

FAMILY SUPPORT
Team members provide support to family members and caregivers through a variety of programs and services.

CLINICAL CARE
The Chapter partners with distinguished medical institutions to provide clinical care in Kansas City, Omaha, Columbia, Springfield and Wichita.

RESOURCES & REFERRALS
We help link families to resources, navigate complex health, legal, financial and social systems,

EQUIPMENT & ADAPTATIONS
Our program helps identify needs and avenues for acquiring necessary equipment, home adaptations and communication devices.

EDUCATION & OUTREACH
Our team provides presentations to raise awareness of ALS to healthcare professionals, legislators or the general public.

Sarah Nauser - Olsen
The 2019 Recipient of the Tom Watson Award for Courage
WHAT WE DO

PROGRAM NUMBERS

Our Chapter served 756 people with ALS in 2019

Cared for 370 patients in our multidisciplinary and care centers

 Loaned out 310 pieces of durable medical equipment

Provided 258 people with Quality of Life Grants

Engaged in 5,035 consultations with patients, their caregivers and families

Client Growth

Find us on Facebook: @ALSMidAmerica
Volunteers are the backbone of success at our events. We thank the army of people who tirelessly give their time and talent.

The Walk to Defeat ALS is the national signature event of The ALS Association and the largest source of revenue for The Chapter.
**PROGRAM FOCUS**

**QUALITY OF LIFE GRANTS: PROVIDING FINANCIAL HOPE**

**OUR GRANTS**

<table>
<thead>
<tr>
<th>Maximum Grant Request Amount</th>
<th>Total Number of Grants Submitted</th>
<th>Total Amount of Dollars Awarded</th>
</tr>
</thead>
<tbody>
<tr>
<td>$400</td>
<td>258</td>
<td>$103,200</td>
</tr>
</tbody>
</table>

**THE PURPOSE**

“Even though its a minimal amount compared to what we pay out of pocket, it’s nice to have this little bit to go towards medical or travel to get out and see family. I guess it’s nice to know that there is at least someone helping those with ALS and giving out grants.”

**THE RESULT**

“So thankful for the grant - we didn’t know that any help was available. A blessing! With us now only bath help is needed- ALS (Association) has helped with their loan closet for other things- Great! Much more ahead of us. Thank you.”

**GRANT IMPACTS BY THE NUMBERS**

191 Requests for Home Modifications

223 Requests for Transportation Assistance

209 Requests for Respite or In-Home Care

144 Requests for General Assistance

134 Requests for Communication Devices

“ALS is a costly disease. It also requires many hands and hearts to support the patient. These funds are helpful. Thank you.”

- Jay Peterson

Providing an annual $400 grant to families to deliver assistance for a number of items needed to make the home safe, provide transportation to and from clinic or to help with necessary equipment or any of a number of other critical items.
“WHAT AN AMAZING OPPORTUNITY WE HAVE... TO CHANGE THE WORLD.”
- Pete Frates
(12/28/1984-12/9/2019)

The Mid-America Chapter joined the entire ALS community in celebrating the life of one of the founders of The ALS Ice Bucket Challenge, Pete Frates. His mother Nancy was our distinguished guest at the 2019 Night of Hope.