

The ALS Association Mid-America Chapter. 1

2017

The ALS Association  
Mid-America Chapter

# Annual Report

COMPASSION  INTEGRITY  URGENCY

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# President's Letter

The ALS Association Mid-America Chapter continues to deliver quality care and support for our clients and their families. Change is the only constant in life and we saw a change in leadership at the National office with Calaneet Balas becoming the new President & CEO. We were fortunate to have Calaneet participate in our strategic planning retreat to develop a new three-year plan more closely aligned with the new National strategic plan. Colleen and Chapter staff have subsequently developed the operations plan to implement strategic objectives. My personal thanks to the Board of Directors and the staff in the time and efforts engaged in this important work.

A primary focus for my term as President of the Board was to work with Colleen in solidifying our various offices to function as one Chapter. Technology has overcome geographic boundaries to enhance communication and collaboration between offices. I have increased my attendance at Regional Advisory Committee meetings by phone and in person. Evidence of progress on this front was confirmed by Chris Tonniges becoming President-elect for The Mid-America Chapter. When he assumes the role of President in February 2019, it will be the first time a Board President from outside the Kansas City area will serve in this role.

The Board of Directors thank all of our donors, corporate sponsors, and volunteers for making it possible to serve our ALS community!



Dr. Keith A. Gary, PhD  
President of the Board

# Letter from the Director

2017 was a year of excitement and success. In the spring, Radicava was approved for use in the United States by the FDA. After 22 years, our ALS community finally had a new therapy shown to slow progression. In the summer, The Chapter's Walks were able to hit the \$1 million fundraising mark, the first time since 2014. Fall brought the culmination of a decade's work in Wichita, KS with the October opening of a telemedicine multi-disciplinary clinic. This clinic, which was awarded The ALS Association's Innovation Award, is a twist on the typical telemedicine clinics with the neurologist attending remotely while the patient and allied medical professionals are local.

The year brought more than just help for today, it also brought a new hope for tomorrow. Realizing and understanding that clinical care and research are truly interdependent, the trajectory of the Chapter has changed. Currently we have six treatment centers, with a vision of more in the future. These hubs of resources for care and research throughout the three-state Chapter area will become even more necessary and valuable.

As we close 2017, I recognize the great successes this year have been made possible by the hard work of so many – staff, Board of Directors, volunteers, donors, advocates and champions. To all of you, I say thank you. Together we do so much.

Now together, let's leverage this momentum into continued growth - in care, in research, in advocacy.

*Colleen E. Wachter*

Colleen E. Wachter  
Executive Director

Our Vision:  
Create a World  
without ALS

Our Mission:  
To discover  
and a cure for  
to serve, advocate  
and empower  
affected by  
their lives to

### Guiding Principles

People with ALS and their families come first

One team, one vision, one mission

Accountability and transparency

Diversity and inclusion

Open communication and dialogue

Innovation

Collaboration

Mission:  
Discover treatments  
for ALS, and  
advocate for,  
empower people  
affected by ALS to live  
their lives to the fullest.

## What We Do

Established in 1985, The ALS Association is the only national non-profit organization fighting Lou Gehrig's Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

As the preeminent ALS organization, The Association leads the way in research, care services, public education, and public policy — giving help and hope to those facing the disease. The Association's nationwide network of chapters provides comprehensive patient services and support to the ALS community. The mission of The ALS Association is 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.

# Board of Directors

Keith Gary,  
President

Suzie Apel,  
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Pete Story

Chris Tonniges

David Wurth

**The Board of Directors is  
comprised of 20 men and women  
dedicated to finding a cause of and  
cure for ALS.**



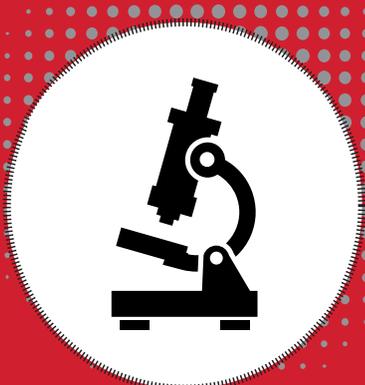
# Three Mission Pillars



## Care Services

The ALS Association helps people living with ALS and families cope with the day-to-day challenges of living with ALS by providing information, resources, and referrals to many sources, including a wide variety of community services.

Our network of chapters provides support in communities across the country.



## Research

Our approach is simple and has led to some of the biggest research discoveries in the history of ALS. We fund the best, most promising research around the globe, while inspiring and initiating innovative partnerships across all sectors – government, industry, academia, and other nonprofit organizations – while funding bright, young scientists to spur innovation.



## Public Policy

The Association's network plays a lead role in advocating for increased public and private support of ALS research and public policy initiatives that responds to the needs of people with ALS. Our public policy efforts in Washington, D.C. have raised the profile of ALS at the White House, among members of Congress, and within federal agencies.



# 2017 Highlights

## Night of Hope

More than 500 guests attended the 29th annual A Night of Hope gala. Dressed in their Prom best, they helped raise more than \$150,000.



In May of 2017, the FDA announced that it had approved Radicava, the first new treatment approved specifically for ALS in 22 years.

## Radicava

## Advocacy

Initiatives include:

- Secure Appropriations for Key ALS Research
- Waive the Five-Month Waiting Period for Social Security
- Access to Home Health Services





Chapter friends George Brett and Tom Watson continued their support for those battling ALS by attending the McGuff Golf tournament. They were joined by dozens of celebrities again, including former Chief, Trent Green.

# Walk to Defeat ALS

In November the first telemedicine clinic in Wichita was held. The ALS clinic featured "Robo-Rick," a tablet connected to a neurologist in Kansas City, and multiple medical professionals on-site. The resulting clinic was lauded by clients and medical professionals alike.

# Joe McGuff ALS Golf Classic

Nearly 10,000 walkers at 10 Walk sites raised more than \$1 million in support of The Chapter's local care services and clinics.

# New Clinic



# A Community United

At the heart of this story is a young man – a kid really – who received news generally reserved for people four times his age. He had ALS. How do you, at 15, digest and comprehend that?

“Stephen only cried twice the whole time,” his mother, Lea Ann Nancy, said. “The night we told him he had ALS and during one of his EMGs. Otherwise he never gave up hope for a miracle. He believed in the power of prayer and was going to be the first person to beat this disease.”



Those close to him say he was an amazing person; always the first to welcome a new kid to school. He loved life, saw the good in others and wanted to protect people.

“I remember he asked for a weather radio for Christmas so he would be able to warn his family and friends if bad weather was coming,” Lea Ann said. “And many times we had kids come to us and say Stephen was my friend when no one else was.”

A competitive tennis player, Stephen first noticed he was having trouble with his service motion. His left arm wouldn’t extend. Everyone chalked it up to fatigue from playing many matches in a short period of time. Then, in February 2016, he and his family noticed his left arm was shaking, and he was having trouble holding his beloved mechanical pencil. It was nothing, they thought, that physical therapy couldn’t fix.

When symptoms got worse, the family was referred to Dr. James Collins, MD, a pediatric neurologist in Springfield. On May 25, 2016, just shy of six months after his first symptoms presented, Stephen was diagnosed with Amyotrophic Lateral Sclerosis, an always fatal neurodegenerative disease. In another short six months, on December 13, 2016, Stephen Nancy passed from ALS. The community was rocked.

Michael Nancy, Stephen’s older brother, was a four-year letter winner in tennis at Republic High School. The tennis coach, Dan Vales, called Lea Ann and told her he and the boys tennis coach at Branson High wanted to do something in Stephen’s memory and also to honor a Branson teacher battling ALS as well. Would it be okay, he asked.

The two rivals, Branson and Republic high schools, dedicated their match to fighting ALS. Before beginning, all the players removed their school jerseys and replaced them with Smashing ALS T-shirts. #PlayForStephen was the rallying cry, and \$1,400 was raised for ALS research.



The United States Tennis Association Missouri Section honored the two coaches who organized the event on Nov. 11 with the 2017 Event of the Year Award.

But this community was not done.



Lea Ann got a call from Stephen’s pediatric neurologist’s office saying they wanted to honor Stephen’s memory by forming a walk team in Springfield’s Walk to Defeat ALS®, but needed a team captain. Lea Ann agreed to act as captain, and told everyone “We’re focusing on awareness, not on money this year.”

“It started steamrolling from there.” She says, “There were so many \$25 checks and so many people wanting to get involved.” At the Walk, Team Nancy had more than 70 people walking. All total, the team raised \$13,523 for The ALS Association Mid-America Chapter and was the top fundraising team. “It made me and so many others happy to remember Stephen and to do something to fight ALS.” Lea Ann says, “Next year we’ll do even more.”

# A Legacy of Help

When you have three kids, a husband with a terminal disease and a full-time career, there isn't much time left for you. Emily Jennings, in that situation relied on her community. "I couldn't have done it without my friends. My family, brother-in-law, my sister and friends that just came out of the woodwork."

20 years later that community continues to



support Emily and her family when they walk in the Walk to Defeat ALS®, as well as many other ways. "Every year the walk

is different," Emily says, "What can we do to make it fresh? Each of my children take turns writing letters to our friends and family who have been contributing. We continue to tell our story." That support is evident in the results they have achieved over the years: raising nearly \$300,000 for The Chapter.

The inspiration for the family to work to raise awareness and dollars to fight ALS comes directly from John. Emily recalls "Once we came to grips with it, then John was like 'ok, I'm in all the way.' He was just determined to find a cure; help people find a cure for this horrible thing."

In addition to the Walk the family has made trips to Washington, D.C. to advocate on behalf of people living with ALS, sits on various committees and the Board of Directors and acts as ambassadors for both The ALS Association and those battling ALS. For 20 years they have taken John's memory and made it his legacy to help.



# Chase the Sun

Before her diagnosis, Jennifer Beckerman was an athlete, avid motorcyclist, mother, volunteer and eternal optimist who believed in giving back and paying it forward. Then, on Dec. 9, 2015, she received her diagnosis of ALS.

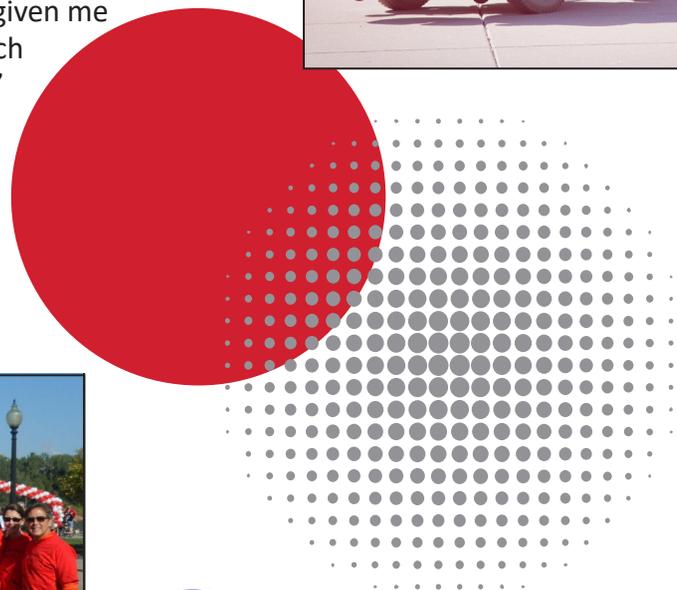


"It was an insignificant day until it became significant," she said.

Now Jennifer Beckerman is a fan of her daughter's mad soccer skills and loves riding on the back of her boyfriend's motorcycle. She is a mother, volunteer and eternal optimist who believes in giving back and paying it forward.

"Nothing has changed. I've just added three letters to my life," she said. "ALS has not changed my goals. I just live my life in a more swift fashion to make sure things get accomplished."

Since her diagnosis, Jennifer has gone to Sturgis, sat on the beach in Mexico and continues to 'chase the sun.' "I have found so much kindness being in this chair," she said. "I would never have wished for ALS, but somehow it has given me so much more."



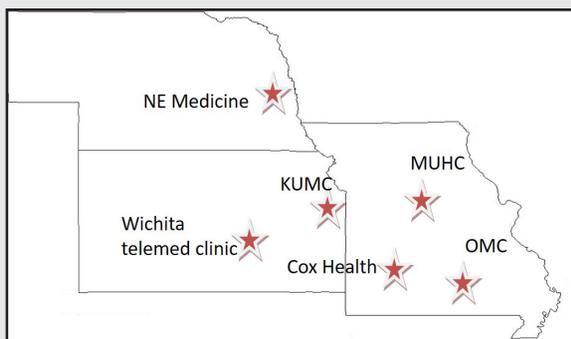
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The ALS Association collaborates with some of the best ALS physicians and clinics across the United States to help ensure that people living with ALS have access to specialized care, based on best practices. The ALS Association's Certified Treatment Centers of Excellence and Recognized Treatment Centers provide compassionate care in a supportive, family-oriented atmosphere.

This multidisciplinary care model brings together a team of health care professionals specially trained to address the needs of people living with ALS, allowing them to receive care from each discipline during a single visit. The care team typically includes a neurologist, physical therapist, occupational therapist, respiratory therapist, nurse, dietitian, speech language pathologist, social worker, mental health professional and an ALS Association Chapter liaison.

# New Wichita TeleClinic



In 2016 The ALS Association Mid-America Chapter began dreaming of opening a telemedicine clinic for people living with ALS in Wichita. Studies have shown that attending an ALS specific multi-discipline clinic prolongs lifespan, and increases quality of life when attended regularly.

Fortunately, The ALS Association has a great champion, Dr. Richard Barohn. Dr. Barohn is Vice Chancellor for Research at the University of Kansas Medical Center in Kansas City, and a long-time ALS clinician and researcher. Seeing the need for clinical services in central Kansas, he volunteered

to spearhead a project to bring telemedicine into Wichita, and to act as clinical director for the new clinic.

A series of partnerships with local medical professionals began, technology was purchased and tested, and about a year after the dream began, it was realized. On November 9, 2017 the first Wichita teleclinic was held, and the initial reviews were outstanding.

The Wichita clinic is still in its infancy, but Jack Wilson, a Wichita resident who has been battling ALS for more than seven years says, "Oh boy, what a wonderful ALS Clinic visit. Saw the whole team today. They all showed up for just little old me. Even through ice and snow, it was so much easier and quicker than going to KC. I liked how we meet with the doctor via videoconference and having the whole team present during the interview. Wichita's clinic rocks...wonderful team."

The unique nature of the clinic set up and partnerships earned The Mid-America Chapter The ALS Association's annual Innovation Award. This prestigious honor recognizes trailblazing chapters who are actively developing and implementing new ideas and/or methods in the delivery of The Association's mission priorities. Colleen Wachter, Executive Director of The ALS Association Mid-America Chapter, accepted the honor on behalf of The Chapter. Of the award she says, "This is a great credit to our Care Services Team, and to Dr. Richard Barohn for his leadership and willingness to champion the project."



# Financial Highlights

Thank you to these donors who, through their generosity, have assisted The Chapter in supporting people and families battling ALS.

## **\$100,000 and above**

Anonymous  
Lattner Family Foundation

## **\$25,000 and above**

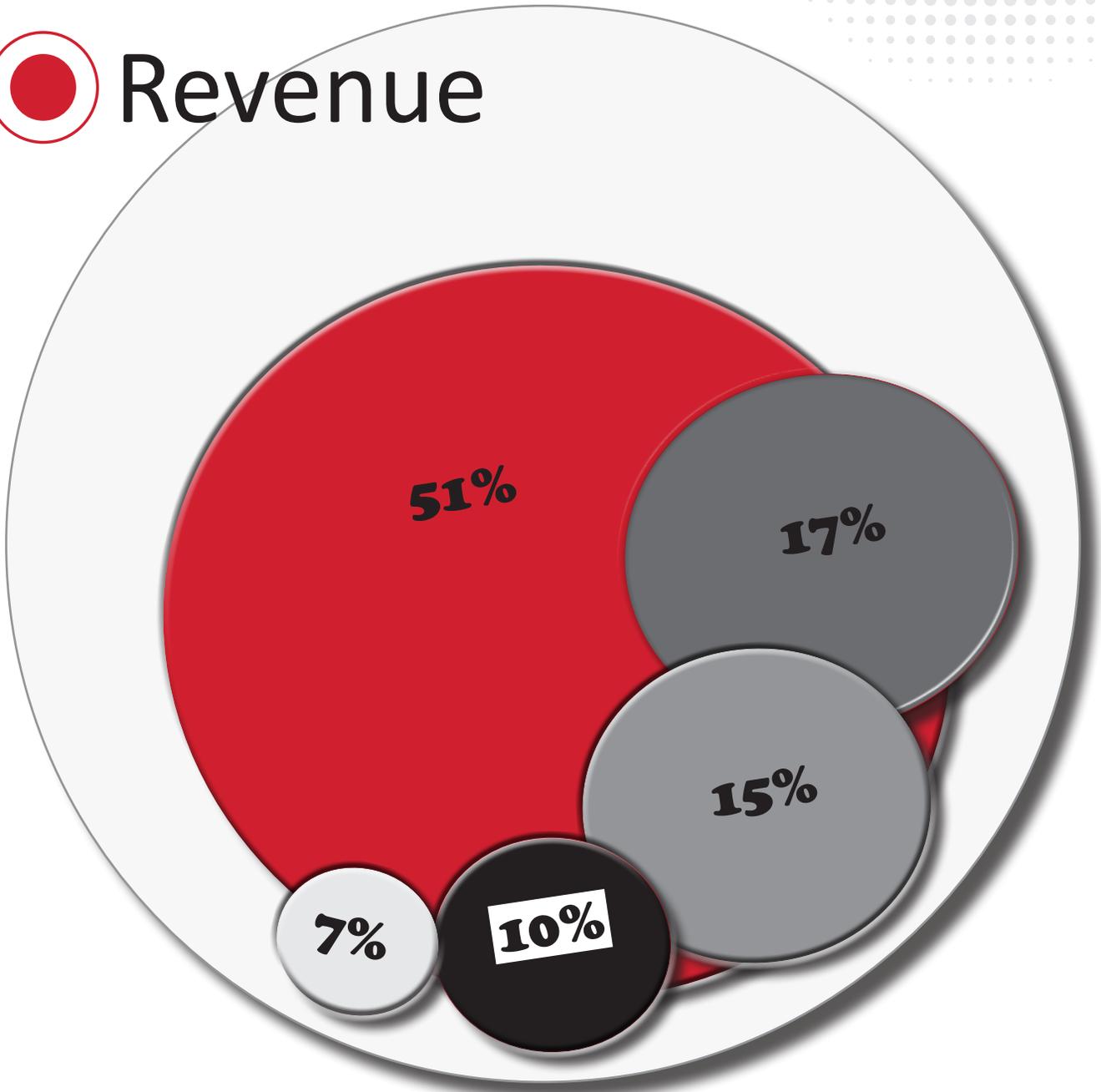
Davis Bethune & Jones LLC  
Isaac Family Institute of Charity  
Stephen L. Clark Family Partnership

## **\$10,000 and above**

Gilbert & Joanna Adams  
American Central Transport  
Jane Bennett  
Blue Cross & Blue Shield of Kansas City  
JE Dunn Construction  
Diana & Jason Kander  
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Lockton Companies, LLC  
Bruce & Janet Longenecker  
Mary Jo & Robert W. Loyd  
Mann Family Foundation  
Murphy-Hoffman  
Grover & Mary Beth Simpson  
TECH Inc  
Teva Neuroscience



# Revenue



## Walk

The Chapter hosts 10 Walks throughout The Chapter service area. It is the national signature event of The ALS Association and the largest source of revenue.

## Individual Gifts

Include memorials graciously directed to The Chapter by families, workplace giving campaigns, and one-time or recurring annual gifts.

## Other Events

Include The Joe McGuff ALS Golf Classic, A Night of Hope gala celebration and third-party events hosted by community members who want to hold an event and designate the funds to The Chapter.

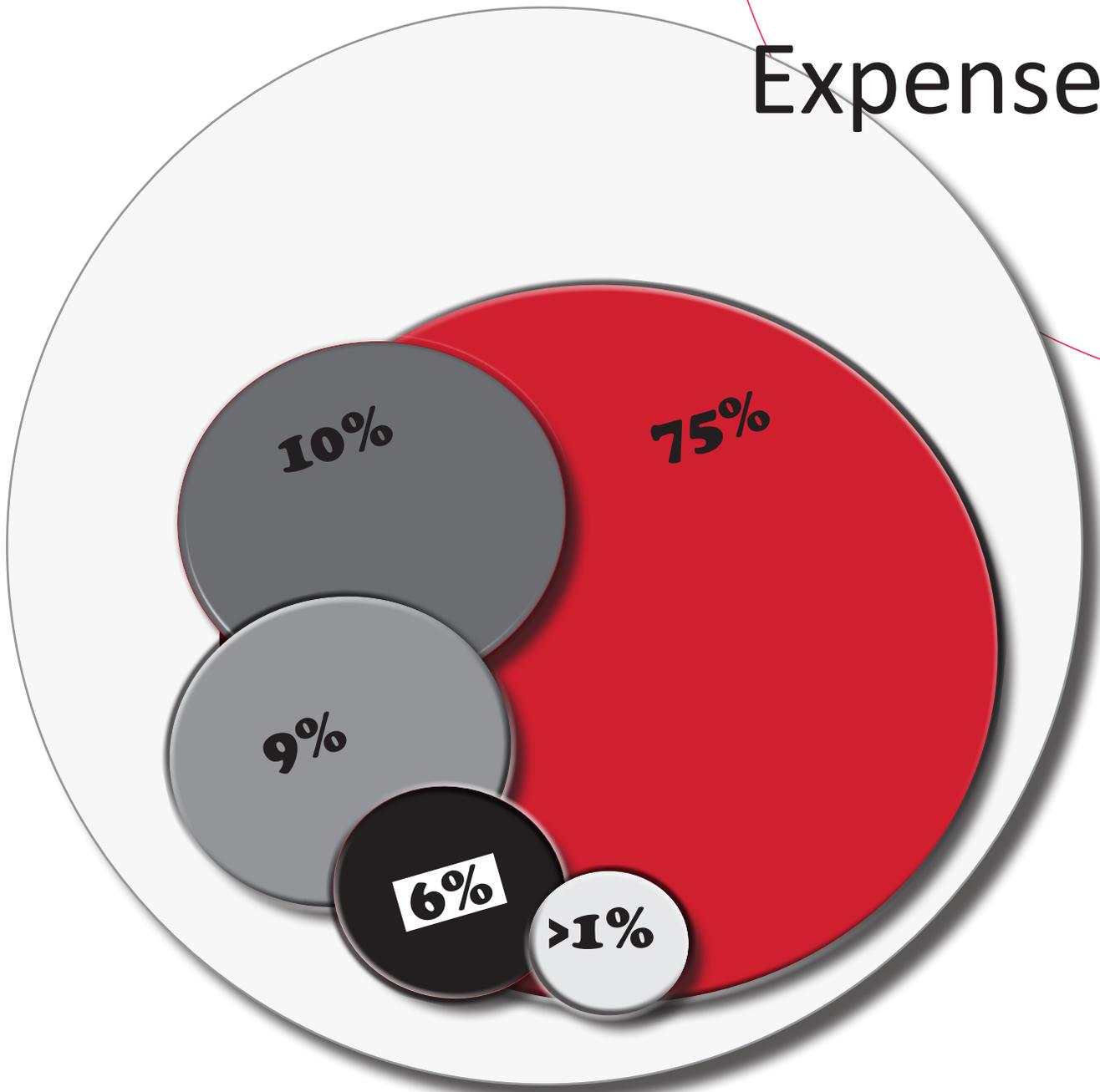
## Pledges

Promises made by donors to fund The Chapter at a set amount into the future. They are a commitment to stand with us as we serve those battling ALS. They ensure future support for families fighting Lou Gehrig's Disease.

## Grants

Are provided by both public and private grantors to support those with ALS through a specific project or program.

# Expenses



## Care services & Education

Includes:  
 Consultations  
 Clinic Follow up  
 Family Support  
 Equipment & Adaptations  
 Resources & Referrals  
 Education & Outreach

## Fundraising

Is critical to supporting our mission and allowing us to serve families battling ALS with sustainable programs and services.

## Administration

A critical component in supporting our mission and focusing our efforts on those we serve and to engage the ALS community.

## Multi-Disciplinary Clinics

Have been shown to increase quality of life and longevity. The clinic includes a neurologist and six additional health professionals specific to ALS.

## Research

Supports the worldwide cutting-edge research program driven by The ALS Association.

You can view The Chapter's most recent 990 at [alsa-midamerica.org/publications](http://alsa-midamerica.org/publications)

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**Chapter**

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