



IMPACT REPORT

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 LETTER FROM THE DIRECTOR

Dear friends,

Looking back on our fiscal year that ended on January 31, 2020, we are so proud of our efforts in helping people impacted by ALS. In 2019 we marked 28 years of service to our pALS and their families in the state of Arizona. Our dedicated staff and volunteers have done an incredible job expanding and strengthening our programs and services.

We continued to collaborate with some outstanding community partners including Ability Center, Barrow Neurological Institute, Bell Lexus North Scottsdale, BHHS Legacy Foundation, Honor Health, Infiniti of Scottsdale, Mayo Clinic, MT Pharma, National Bank of Arizona, Nextiva Cares, Numotion, Permobil Foundation, Quantum Rehab, Tucson Electric Power, United Access, Valley Toyota Dealers, and many more. And finally, both Bite Nite and The Walk to Defeat ALS saw a record number of participants not only helping raise funds, but spreading awareness of ALS in the community.

This report highlights some of the many people that helped us accomplish these goals and serve our incredible community. It is a snapshot of the successes had, the awareness raised, and the lives affected.

From all of us at The Arizona Chapter, thank you for your support of our mission to serve and empower people affected by ALS to live their lives to the fullest. We hope you will continue to join us in the fight against ALS.



Sincerely,

A handwritten signature in black ink that reads "Taryn Norley". The signature is fluid and cursive, written in a professional style.

Taryn Norley

YOUR IMPACT IN ARIZONA

Our chapter uses your contributions to support patient services, caregiver programs, and education for people with ALS (PALS) and their families living in Arizona. Thanks to your generous donations, The ALS Association Arizona Chapter was able to provide the following services at no cost to PALS in 2019:



\$675,422

total spent on programs and services for PALS and their caregivers



141

new PALS served



144

home visits provided

505

PALS appointments at multidisciplinary ALS clinics

122

transportation trips provided to PALS



91

ALS support group meetings



1,445

hours of respite care provided



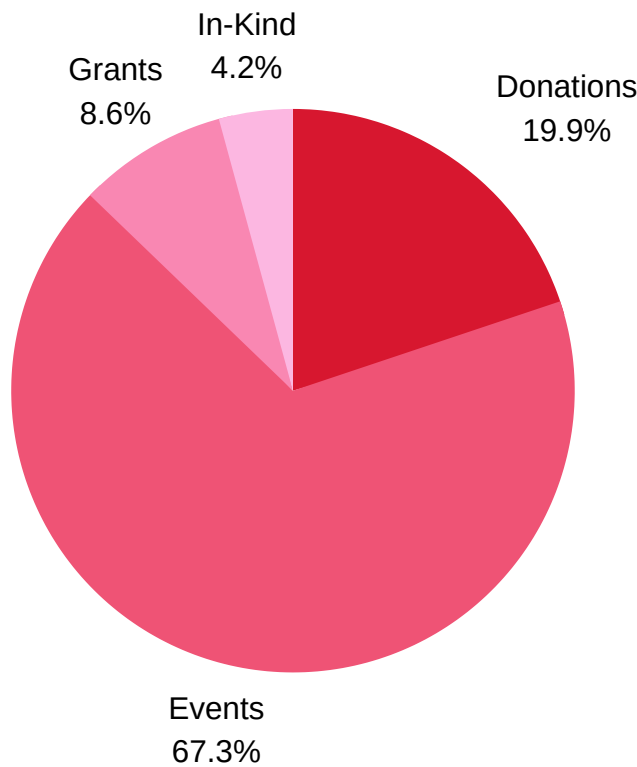
550

hours spent helping patients with respiratory needs

THANK YOU!

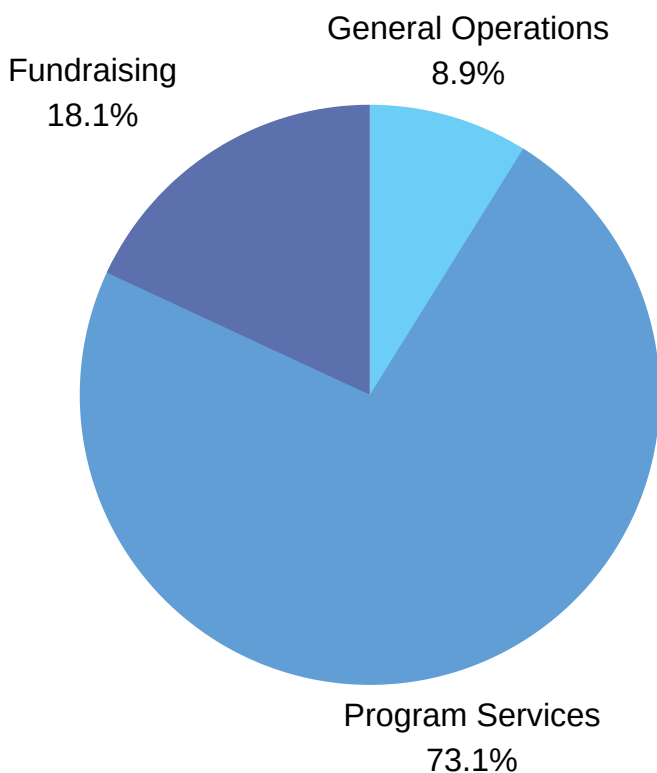
FINANCIALS

As a 501(c)(3) organization, we depend upon the generosity of individuals, corporations, foundations, grants, & community partners who provide us with tax-deductible contributions so that we may support our ALS community.



Revenue

- Donations (\$359,424)
- Events (\$1,218,541)
- Grants (\$154,878)
- In-Kind Donations (\$76,731)



Expenses

- Program Services(\$1,308,081)
- Fundraising (\$323,694)
- General Operations (\$158,755)

For a copy of the Chapter's Form 990 or most recent audit, please contact our office.

ALS MULTIDISCIPLINARY CLINICS

ALS multidisciplinary clinics bring together a team of healthcare 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, assistive technology specialist, and ALS Association Chapter liaison. We also have a contracted counselor and child life specialist as needed by referral. The ALS Association Arizona Chapter works with three different ALS certified multidisciplinary clinics. These are the Gregory W. Fulton ALS Center at Barrow Neurological Institute, HonorHealth ALS Clinic, and the ALS Clinic at Mayo.



BARROW NEUROLOGICAL

The Barrow Neurological Institute at the Fulton Center is run by Dr. Ladha and his team of multidisciplinary experts. Dr. Ladha has been seeing ALS patients at this clinic for 13 years. The clinic follows around 250 patients at any given time. They see 100 new patients a year and between 10-20 ALS patients a week. Dr. Ladha has also served as a Co-Chair for our Bite Nite fundraiser.

HONORHEALTH

Dr. Levine and his team at the certified HonorHealth Neurology clinic have been working with our ALS patients for many years. The clinic meets once a week on Wednesdays, and they'll typically see about five patients that day. Everyone on the team has years of experience working with ALS patients. Dr. Levine served as the Event Chair for the 2019 Bite Nite fundraiser.

MAYO CLINIC

Mayo Clinic doctors across the country diagnose and treat more than 800 people with ALS each year! The Mayo Clinic in Arizona, led by Dr. Muzyka and Dr. Ross, was ranked highly performing for neurology and neurosurgery by U.S. News & World Report. Dr. Ross served as a Co-Chair for Bite Nite in 2012 and Chair in 2013.

CLINIC CARE MODEL



NEUROLOGIST

ALS expert and leader who oversees, evaluates, and manages a patient's condition



DIETITIAN

Educates and helps a patient maintain optimal nutrition, hydration, and weight



RESPIRATORY THERAPIST

Evaluates a patient's breathing and educates on respiratory assistance



SPEECH LANGUAGE PATHOLOGIST

Monitors a patient's swallowing and speech and helps overcome challenges



OCCUPATIONAL THERAPIST

Evaluates a patient's physical function and recommends equipment to help with independence



ASSISTIVE TECHNOLOGY SPECIALIST

Provides a patient with guidance and recommendations for items to maintain or improve accessibility



PHYSICAL THERAPIST

Helps a patient adjust to changes in physical mobility and maintain muscle strength



NURSE

Manages medical treatment and monitors patient with visits and assessments



SOCIAL WORKER

Helps patients access and best utilize the resources available to them and advocate on their behalf for extra support



CARE SERVICES COORDINATOR

ALS Association representative and liaison that provides a patient with ongoing support and resources to fulfill clinic recommendations

THANK YOU CLINICIANS!

Dr. Shafeeq Ladha
Neurologist

Dr. Todd Levine
Neurologist

Ally Maryska
Respiratory Therapist

Alice Stoner
Occupational Therapist

Dr. Jeremy Shefner
Neurologist

Helena Schmalz
ALS Clinic Coordinator

Nicole Bruno
Social Worker

Dawn Magid
Social Worker

Angela Escalante
Occupational Therapist

Dr. Anne Hatch
Neurologist

Dr. Irina Muzyka
Neurologist

Jourdan Milliard
Nurse Practitioner

Deborah Taylor
Physical Therapist

Ariana Seif-Naraghi
Physical Therapist

Jeri Young
Occupational Therapist

Nancy Rosas
Nurse

Rose Anaya
*ALS/MDA Program
Coordinator*

Melissa Kelley
Speech & Language Therapist

Susan Meland
Physical Therapist

Ricky Moore
Respiratory Therapist

Janice Anderson
Speech & Language Therapist

Neda Zelic
Social Worker

Karen McNett
Speech & Language Therapist

Brandi Soto
Respiratory Therapist

Dr. Mark A Ross
Neurologist

Bill Jacobsen
Neurologist

Jessica Lubold
Dietitian

Bernie Miller
Respiratory Therapist

Lori Heath
Dietician

Katie Ramnath
Nurse

Dr. Irina Muzyka
Neurologist

SUPPORT GROUPS

We are so proud to offer monthly support groups in areas throughout Arizona. These meetings can be educational gatherings, safe places to express emotions, or forums to share experiences and information. PALS, caregivers, family, and friends are welcome to attend and to give and take the wisdom and experience that comes from living with a devastating illness. We offer general support groups for PALS, Caregiver support groups, and Page 2, a support group for survivors. These take place all over the state for the convenience of our community.

"After the diagnosis, meeting staff through the ALS Association has been extremely helpful with navigating this journey we are on. We've been to Caregiver meetings and Patient meetings and found them to be comfortable, inviting, informative, and enjoyable!"

"The ALS Association gave me people to confide in, and when I was younger simply gave me a place to distract myself from what was happening to my dad. I'm so glad that throughout the years I've had a place to go where there are always people I can talk to no matter what."



LIVING WITH ALS



This unique program provides fun, interactive leisure activities that allow families to connect with peers in a non-threatening atmosphere.

This year we were able to provide many activities for our PALS! These included, horseback riding, adapted fishing, adapted golf, adapted water sports, and adapted air rifle shooting.

"I was hesitant to join the Living With ALS group, but it's one of the best decisions I have made. I am not dying, I am living every day to the best of my ability and having a blast. When I was diagnosed, I never thought I would say that!"



Special thanks to:

Arizona Coyotes Foundation



YOUTH PROGRAM

Our ALS Youth Program helps support kids ages 6-18 by hosting fun, high-energy events that give them a break from the realities of ALS and enable them to build lasting relationships with peers who understand their struggles.

This year we provided multiple bonding opportunities for our Youth Program. These included Family Field Day Baseball Game, Kid's Day Out, Volunteering at Midwest Food Bank, Teen Adventure Day, and Memory Maker's Weekend. We also provide monthly Teen Talks. These are discussions about coping, grief, and loss for teenagers who are learning to navigate their loved one's journey with ALS.

This year 28 families including 59 children and teens participated in our programs!

"I was 5 years old when my father was diagnosed with ALS, and to say the least it shook me to the core. We were so close and did everything together and to watch him get so sick was awful. The ALS Association gave me people to confide in, and a place to distract myself. I'm so glad that throughout the years I've had a place to go where there are always people I can talk to, no matter what. As I have gotten older and have met new kids going through this, I am able to share my experience with them and be a person to listen."

Special thanks to:
BHHS Legacy Foundation
Charros



OTHER PROGRAMS

In addition to our Multidisciplinary Clinics, Support Groups, Living with ALS, and Youth Program, the programs below are offered for free to our PALS. These are facilitated by our chapter staff as well as contracted employees to ensure that patients are receiving the best information and care.

ALS 101

These classes address questions and connect recently diagnosed patients with programs and resources

TRANSPORTATION

Wheelchair accessible transportation to/from clinics is available for patients that are unable to acquire an accessible vehicle

CARE CONSULTS

Care Services Coordinators work with families to provide health education, emotional support, and assess needs

NURSE CONSULTS

Consultations with an ALS nurse educator are available on an as-needed basis to address questions about ALS progression

EQUIPMENT LOAN

Durable Medical Equipment ranging from \$25- \$30,000 is provided to patients in need through our Loan Closet at no cost

CHILD LIFE SPECIALIST

We provide families with age-appropriate counseling services to support youth facing the realities of their loved one's diagnosis

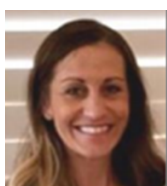
PATIENT COUNSELING

Counseling services are available to assist patients and their families with addressing the challenges of an ALS diagnosis

RESPIRE CARE

The Respite Care program provides breaks for family members who are giving constant care to their loved ones

CONTRACTED STAFF



JAYMEE MACTURK
Child Life Specialist



JANIE DARLYMPLE
Nurse Educator



JILL CANDLAND
Youth Coordinator

JULIE GELL
Counselor

DAWN MAGID
Counselor

DICK HECKEL
Respiratory

ALS ADVOCATES

Every year, hundreds of ALS Advocates come to Washington, D.C. to learn about the latest ALS research, network, visit Capitol Hill, and share their stories with members of Congress to gain legislative victories. The 2019 National ALS Advocacy Conference focused on education, advocating, and mobilizing all members of Congress in a bipartisan fashion to achieve the mission of The ALS Association. ALS Advocates across the country highlighted the latest information and research from our three mission pillars: Advocacy, Research, and Care Services.



2019 Legislative Asks:

- Waive the Social Security Disability insurance five-month waiting period for people with ALS
- Oppose Centers for Medicare and Medicaid Services decision to add noninvasive ventilators to the Competitive Bidding Program
- Provide \$20 million in appropriations for FY2020 to continue to ALS Research Program for the Department of Defense
- Provide \$10 million in appropriations for FY2020 to continue the National ALS Registry and Biorepository at the Centers for Disease Control and Prevention
- Provide \$41.6 billion in appropriations for FY2020 to allow for meaningful growth above inflation in the base budget that would expand the National Institutes of Health's capacity to support promising scientific disciplines

In June 2019, as a result of the efforts of ALS advocates, over 38 Senators and 178 House members signed a "Dear Colleague" letter urging the Centers for Medicare and Medicaid Services (CMS) to reverse its decision to include non-invasive ventilators in competitive bidding. Additionally, strong bipartisan support increased for the ALS Research Program at the Department of Defense, the National ALS Registry at the Centers for Disease Control and Prevention, and the National Institutes of Health for the federal fiscal year 2020, which ran from October 1, 2019 to September 30, 2020. Hill visits made by advocates, as well as emails from across the country, made major difference in securing Congressional support.

GLOBAL IMPACT OF RESEARCH

Since 1985, The ALS Association has been at the forefront of ALS research. We pursue an agenda of effective and rigorous research to understand how ALS works and how it might be treated, and to improve the lives of people living with ALS today. Though we are the world's largest philanthropic funder, the scientific challenges posed by ALS are far bigger. We fund what we can, coordinate with other funders on the projects we cannot directly support, and invest in the people and infrastructure needed to make ALS research efficient and effective.



11

NEW ALS GENES
IDENTIFIED SINCE
2014 ALS ICE BUCKET
CHALLENGE

33+

ALS DRUG TRIALS

9

NEW GLOBAL
STRATEGIC INITIATIVES
LAUNCHED OR
SUPPORTED

64+

NEW GLOBAL
RESEARCH
PROJECTS
AWARDED

169

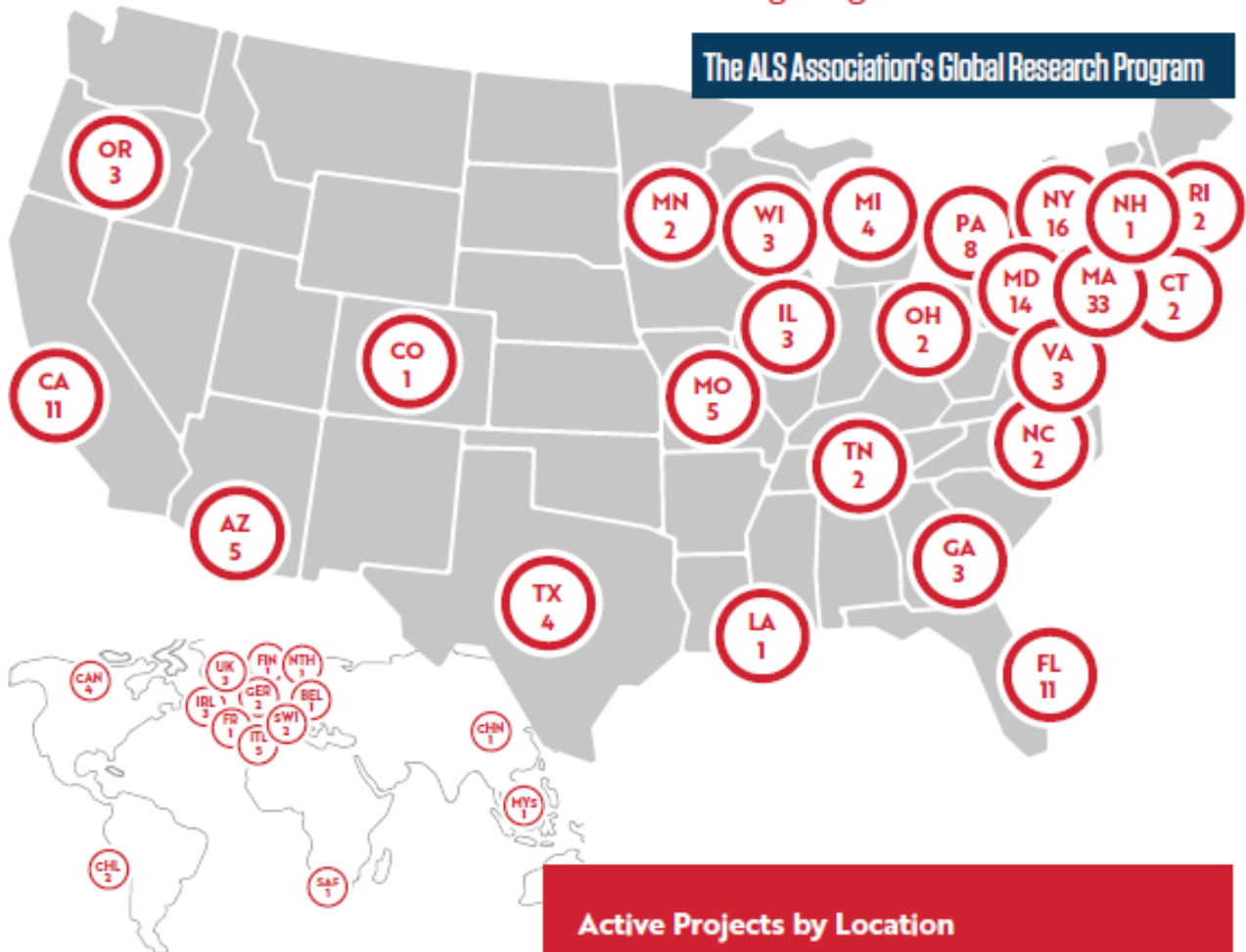
ACTIVE RESEARCH
PROJECTS AS OF
2/3/2020



CURRENT PROJECTS

The ALS Association is Accelerating Progress Toward Treatments

The ALS Association's Global Research Program



169 Active Research Projects

In an effort to accelerate progress toward finding treatments and a cure for ALS, as of 02/03/2020, The ALS Association is currently funding 169 active research projects total. There are 141 within the United States.

Active Projects by Location

Arizona - 5	New Hampshire - 1	Belgium - 1
California - 11	New York - 16	Canada - 4
Colorado - 1	Ohio - 2	Chile - 2
Connecticut - 2	Oregon - 3	China - 1
Florida - 11	Pennsylvania - 8	Finland - 1
Georgia - 3	Rhode Island - 2	France - 1
Illinois - 3	Tennessee - 2	Germany - 2
Louisiana - 1	Texas - 4	Ireland - 3
Massachusetts - 33	Virginia - 3	Italy - 5
Maryland - 14	Wisconsin - 3	Malaysia - 1
Michigan - 4		Netherlands - 1
Minnesota - 2		South Africa - 1
Missouri - 5		Switzerland - 2
North Carolina - 2		United Kingdom - 3



The ALS Association Core Values: COMPASSION. INTEGRITY. URGENCY

ALS.org

02/03/2020

PALS STORIES

Gabe & Michelle Tapia

We were privileged to have the Arizona ALS Association sponsor our trip to Washington DC last year for Advocacy. It was an amazing experience for us both. We met so many wonderful people living their lives with ALS and learning their stories and how this horrible disease has impacted and devastated their everyday lives.

The highlight of the trip was actually going to Capitol Hill and meeting with our Arizona senators, congressmen and share with them how this disease has impacted not only me but how this has affected my wife, my kids, and my parents.

To explain to the Senators and congressmen the pain I see in my family's eyes when I try to enunciate words when I speak to them is just devastating to me.

When meeting with our state political officials I was pleasantly surprised to learn that they are very knowledgeable about ALS. For example congressman Andy Biggs, after learning how quickly ALS progresses in our bodies and how it devastates families, was motivated enough to chair the newly formed ALS caucus in Congress. Congressman David Schweikert, after doing his research, felt like science is about 2 years from having a viable treatment for ALS but his big concern was, how we are going to pay for the treatment for all pALs.

I feel like the annual pilgrimage the ALS Association makes to the nation's Capitol has made a huge impact and has forced our political leaders to pay more attention and educate themselves of the cruelty of this disease.

We had a lot of fun in DC. My wife and I booked our trip 3 days before the conference so we can take in some sightseeing. We visited the Smithsonian aeronautical Institute, the Lincoln Memorial, the Washington monument, the Vietnam Wall, Ford's Theater and we still didn't see everything we wanted to see. I know DC gets a bad wrap and is known as the "swamp", for all the political shenanigans that go on (being nice), but I felt very humbled to be in our nation's most historic city, where the laws of our great land were framed.

We would encourage anyone considering the opportunity to visit DC for Advocacy to take advantage of this opportunity and take in the entire experience.



PALS STORIES

Maceo Carter

A fork, knife, and spoon are what started this journey. When I was diagnosed with ALS on November of 2016 hope, help, and joy exited the stage and left immediately. That was until we moved out to Arizona and became a part of The ALS Association Arizona Chapter's community. The utensils, iLevel power wheelchair, bidet, and other items loaned to us from the loan closet are essential parts of my daily life. Something as simple as a fork, knife, and spoon represented the hope and the help this organization provides to our community. The programs that cater to the whole family are outstanding with activities such as baseball games, family making memory retreats, fishing and horseback riding provides joy you would never think could exist. This chapter and its offerings define what "Living with ALS" can be for thousands of people.





**WALK TO
DEFEAT ALS**

\$639,115



BITE NITE

\$490,550



**THIRD-PARTY
EVENTS**

\$131,062

SCOTTSDALE WALK TO DEFEAT ALS



\$473,305 RAISED • 1,304 PARTICIPANTS • 140 TEAMS

TOP TEAMS

- | | |
|--------------------------------------|----------------------------------|
| 1. Team Vanessa \$141,000 | 6. Chad's Ninjas \$11,560 |
| 2. Ray's Rebels Against ALS \$24,024 | 7. Jim Dandy \$11,154 |
| 3. Keniston's ALStars \$22,260 | 8. Iron Horses \$10,289 |
| 4. Team Proudfoot \$21,705 | 9. Team Fab Five for ALS \$8,911 |
| 5. Cathy's Crew \$13,008 | 10. Doug Outs \$8,620 |

TUCSON WALK TO DEFEAT ALS



\$165,809 RAISED • 350 PARTICIPANTS • 44 TEAMS

TOP TEAMS

1. Lady Baba's Band of Beauties \$50,345
2. Josh's Fearless Fighters \$28,520
3. Kay's Shining Stars \$23,453
4. Team McDonald \$14,400
5. Doreen's Team \$11,750

OUR STAFF



TARYN NORLEY
Executive Director



AMY FRANK
Director of Care Services



AMBER MONTANEZ
Care Services Coordinator



MA'AYAN MAOZ
Care Services Coordinator



ANGIE TIGGES
Director of Special Events



BEKAH BARAJAS
Office Manager



JANIE DARLYMPLE
Nurse Educator



RONDO SMITH
Respiratory Therapist

BOARD OF DIRECTORS



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Chair
Ketch 22



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Barrow Neurological Institute*



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Infiniti of North Scottsdale



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University of Arizona*



Scott Sutherland
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Trevor Davenport
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Technologies*

Stewart Proctor



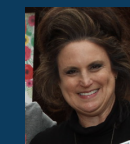
Shelley Hearn
City of Tempe



Mark Hutchins
My Home Group



Anthony Peterson
Treasurer
Arizona Business Bank



Allison Pogemiller
ALS Connect, LLC

THANK YOU SPONSORS!

IN 2019, THESE CORPORATE SPONSORS RAISED OVER \$150,000 FOR OUR CHAPTER.



SPECIAL THANKS TO OUR 2020 ASK THE EXPERTS SPONSORS



UPCOMING EVENTS IN 2020

AUGUST 22

Ask the Experts

Virtual Event



NOVEMBER 14

Walk to Defeat ALS

Scottsdale & Tucson

Virtual Walk



NOVEMBER 28

Bite Nite

Phoenix & Tucson

Virtual Event

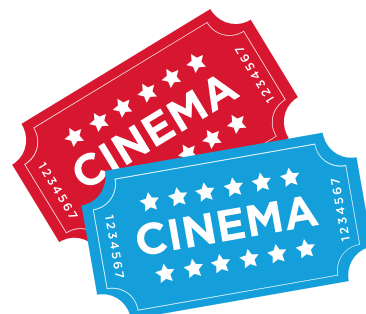


DECEMBER

Drive-in

Holiday Movie

Phoenix



IN LOVING MEMORY

2/1/2019 - 1/31/2020

Mark Adinolfi	Merle Dunaway	Kenneth Kay	Thomas Patterson	Jean Smith
Oliberto Aguila Mola	Frances Fitzgerald	Daniel Kehrberg	Tanya Pea	Dennis Spear
Charles Ainsworth	Michael Fletcher	Jo Laird	Socorro Pena	Gary Thurber
Francisco Arias Pena	Deborah Gall	Judy Landers	Suzanne Penzotti	Charles Tirrito
Peggy Baker	Tim Gardiner	Salvador Larios	Maria Perezderamos	Michael Wald
Robert Balazik	Patricia Gaskill	Mary K LaTempa	Pamela Petriak	Greg Ward
Leonard Basurto	Sheila Gerry	Carolyn Leslie	Gary Phelps	Deborah Watkins
Carlos Benites	Ellen Getz	John Lester	Angela Piner	Charles Weaver
Bert Bonfadini	Martha Gibson	Randy Lien	Jack Porter	Jonah Weber
Thomas Bradford	Donald Goeglein	Carlos Lizarraga	Gloria Price	Norbert Weister
James Braithwaite	Thomas Golis	Jeffrey Lodestro	Greg Price	Paul Weston
Sharon Buckmaster	Kent Gott	Diane Long	Linda Ratliff	Jerome Whalen
David Burkhardt	Brian Grate	Midge Lund	Edwin Reichelt	Rich Whalen
Beverly Campbell	Johnathan Griggs	Brian Mack	John Reiter	Ronald Wheelen
Chad Campbell	Kay Groll	Dora Martinez	Mark Rice	Sandra Whitenack
Steve Carlson	Wallace Gulbrandson	William Martino	Kardith Robertson	James Wigginton
Victoria Catelain	Billie Hartman	Giovanni Maugeri	Patricia Rodriguez	Rosie Wigley
Daniel Catlin	Richard Hayden	Arlene McCarthy	Marlys Ross	Marwood Willard
Jackie Chapman	Donita Hayes	Carol Mcfarland	Dino Roth	Jeffrey Williams
Ed Clark	James Haynes	Eldon McLaughlin	Dawn Rowe-Morling	Norraine Williams
Patricia Conner	Robert Hedlund	Virginia Mendoza	David Saunders	Glenn Williamson
Guy Cournoyer	Linda Hill	James Menking	Terry Schmidt	William Winslow
James Cramer	Eric Hofstetter	Kerry Morrison	Vickie Schuman	Mark Woehle
Loren Crane	Gerald Huffman	Neal Mosley	Rod Seagle	Gary Yearack
Lisa Cunningham	Lois Ingham	Nancy Nowak	Charles Servis	Karen Yoast
Susan Damato	Steve Jacobson	Minnie Oliver	Debra Sinclair	Mildred Young
Donald Doiron	Manuel Jaramillo	Patricia Orazio	Francis Smith	Raymond Zaragoza
				Bette Zimmerman



360 E Coronado Rd, Suite 140

Phoenix, AZ 85004

602-297-3800

info@alsaz.org

alsaz.org