

2021 IMPACT REPORT

Fiscal Year 2021

February 1, 2020 - January 31, 2021



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,

While 2020 looked different at The ALS Association Arizona Chapter, we were grateful to remain open and continue to provide care and resources for people living with ALS and their families. Like most nonprofits, the pandemic forced us to pivot our operations and the way we provide our services. ALS does not stop and neither do we, became a driving force and motivator for our work.

In the face of many overwhelming obstacles, our team came together to reimagine how we serve our ALS families and how we raise funds to continue providing our FREE programs and services. During an extremely isolating time, we continued to provide resources and opportunities for our families to interact and connect from the safety of their homes. Our Care Services team began offering virtual Support Groups and hosted virtual Social Connections events. With clinics not meeting in person, our team organized virtual Care Consults to help provide resources, such as equipment from our Loan Closet Program, to both newly diagnosed and registered families.

The success of our fundraising events in 2019 allowed for us to expand and strengthen the programs and services our Chapter provided but fundraising during a pandemic posed a new challenge. We quickly reimaged our Walk to Defeat ALS to a “Walk Your Way” fundraiser where teams fundraised and then celebrated Walk day however they saw fit. Our Bite Nite gala also went virtual and hosted an online auction, raffle, and program while still keeping with the overall Bite Nite feel everyone has come to love.

This report highlights some of the many ways we continued to serve our incredible community in 2020. 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 written in a cursive, flowing style.

Taryn Norley, President & CEO

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 2020:



\$1,044,980

total spent on programs and services for people living with ALS and their caregivers



638

people living with ALS served



5,676

care consults provided



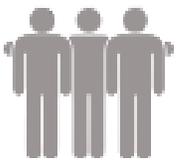
338

virtual appointments at multidisciplinary ALS clinics



1,090

pieces of durable medical equipment loaned



60

ALS support group meetings



1,054

hours of respite care provided



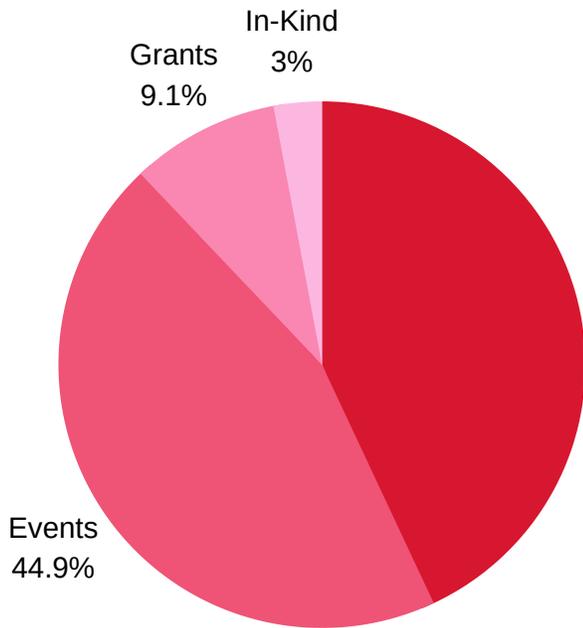
186

hours spent helping patients with respiratory needs

THANK YOU!

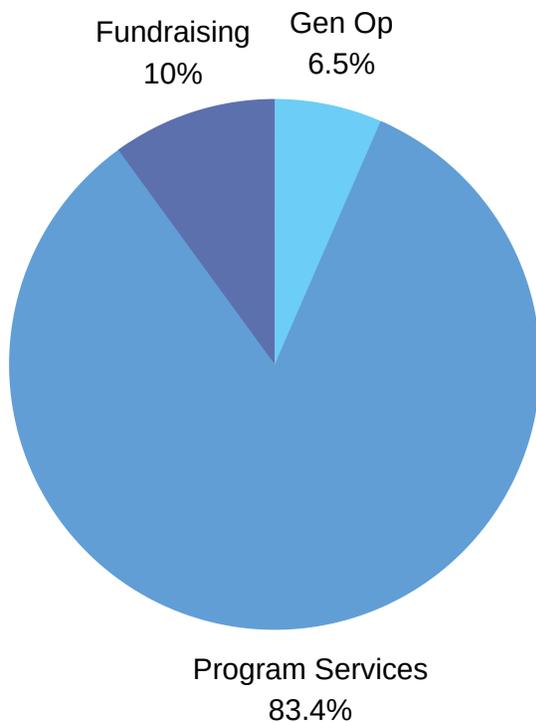
FINANCIALS

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	Donations (\$597,597)
43%	Events (\$623,426)
	Grants (\$126,900)
	In-Kind Donations (\$41,032)



Expenses

Program Services	(\$1,044,980)
Fundraising	(\$125,510)
General Operations	(\$81,826)

TELEHEALTH DURING A PANDEMIC

The Covid-19 Pandemic that hit in early 2020 had a huge impact on the ways in which we serve the families living with ALS in Arizona. We needed to quickly pivot the majority of our programs, services, and events to the virtual world in order to maintain our community of support and hope. Below are a few of the programs that changed this year.

Some switched completely to virtual platforms and video meetings, while others maintained a hybrid structure. While this was much different from how we served people living with ALS in the past, we were so happy to be able to keep our community connected and cared for during this difficult time.

SUPPORT GROUPS

RESPIRATORY & NURSE CONSULTS

CAREGIVER SKILLS TRAINING

ALS CLINICS

SOCIAL CONNECTIONS

ASK THE EXPERTS



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 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.

Once the COVID-19 pandemic hit Arizona, all of the ALS clinics across the state needed to quickly pivot in order to address the unique needs of the patients they served. There had not been a virtual clinic to serve those with ALS prior to this time. Each clinic was able to adapt in a timely manner and change their services to be through telehealth, whether that be through video conferences or phone calls, along with individual doctor appointments as desired. This allowed patients to continue to be followed by their providers, obtain the necessary equipment, acquire appropriate recommendations and adaptations, and receive emotional support, all of which they have come to expect from their ALS clinic. One year after the pandemic started, clinics continue to serve patients through a hybrid of both in-person and virtual services unlike what had been provided prior to 2020. This provides patients with more control over their own healthcare and permits clinicians to be innovative in their approaches. As we transition back to a world without COVID-19, the need for virtual clinics will remain and this technology will continue to serve those who most require it.

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 over 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, was ranked highly performing for neurology and neurosurgery by U.S. News & World Report.

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

Dr. Iryna Muzyka
Neurologist

Dr. Jeremy Shefner
Neurologist

Dr. Anne Hatch
Neurologist

Dr. Bill Jacobsen
Neurologist

CAREGIVER SKILLS TRAINING

These hands-on training sessions teach the techniques of safe and successful caregiving. This class has been designed specifically for family caregivers caring for a person with ALS and addresses important topics including transfers, personal hygiene, communication, emergency preparedness, and more. In 2020, we pivoted this training to a virtual platform, showing video demonstrations and answering questions in a live seminar. Though the hands-on aspect was missing, we were still able to help many caregivers learn to care for their loved ones at home.

ALS 101

Receiving a diagnosis of ALS is challenging and overwhelming. There is so much to learn, a great deal to consider, and typically a lot of questions. This series of classroom-style education sessions is designed specifically for people who have been diagnosed less than 6 months ago and addresses important topics such as programs and services provided by our chapter, Q & A with a neurologist, adapting to change, insurance, legal planning, and understanding research. In 2020, we hosted these classes virtually, ensuring that newly diagnosed patients and caregivers were still receiving the information and resources they needed.



LIVING WITH ALS
RESOURCE GUIDE 1



What is ALS?
An Introductory Resource
Guide for Living with ALS

ALSA.org

ALS
ASSOCIATION

DURABLE MEDICAL EQUIPMENT LOAN

Living with ALS can be expensive, and we recognize the significant role that Durable Medical Equipment (DME) plays in maintaining safety and providing the best quality of life. Our Equipment Loan Program, consisting of over 3,000 pieces of equipment, offers equipment to residents & visitors of Arizona who have an ALS diagnosis. Our loan closet holds a variety of equipment to help with mobility, speech, respiratory needs, smart home technology, and personal tasks. This was especially important in 2020, as patients needed access to proper equipment while staying at home.

RESPIRATORY & NURSE CONSULTS

As ALS progresses, people living with ALS may encounter challenges related to breathing, coughing, and changes in salivation. We provide education with a Respiratory Therapist to assist with managing these symptoms and help guide decision-making about various respiratory support options. When it comes to managing medical symptoms, some challenges are best addressed by a nurse who understands the medical concerns that may arise as a result of ALS disease progression. Our Nurse Educator specializes in ALS and is available for education and training on an individual consultation basis. In 2020, both respiratory and nurse consults took place largely over the phone and through video calls. However, our staff was also able to help in exceptional situations by going into patients' homes that needed immediate help.



OTHER PROGRAMS

In addition to these great programs, the programs below are offered for free to our families. These are facilitated by our chapter staff as well as contracted employees to ensure that patients are receiving the best information and care.

SUPPORT GROUPS

These meetings are offered in many regions across Arizona, and now virtually, and are open to anyone impacted by ALS

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

YOUTH PROGRAM

This program serves youth who have loved ones with ALS by providing fun events & enabling them to build connections with peers who understand their challenges

LIVING WITH ALS

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

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 DALRYMPLE
Nurse Educator



JILL CANDLAND
Youth Coordinator

JULIE GELL
Counselor

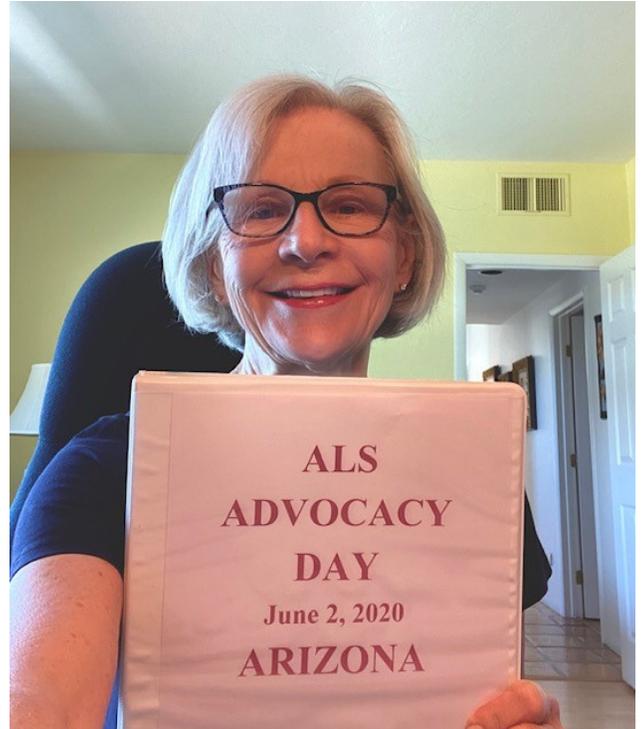
DAWN MAGID
Counselor

DICK HECKEL
Respiratory

ALS ADVOCATES

Every year, hundreds of ALS Advocates join together in Washington, D.C. to participate in the National ALS Advocacy Conference. During the conference, advocates learn about the latest ALS research, gather on Capitol Hill to meet with members of Congress, share personal stories and the impact of ALS on the community.

In June 2020, Arizona advocates were able to participate in the National ALS Advocacy Conference from their own homes. The transition to a virtual platform was challenging, but allowed families statewide to participate because many of the barriers associated with travel were eliminated. The team was able to mobilize all members of Congress in a bipartisan fashion to achieve the mission of The ALS Association.



2020 Legislative Asks:

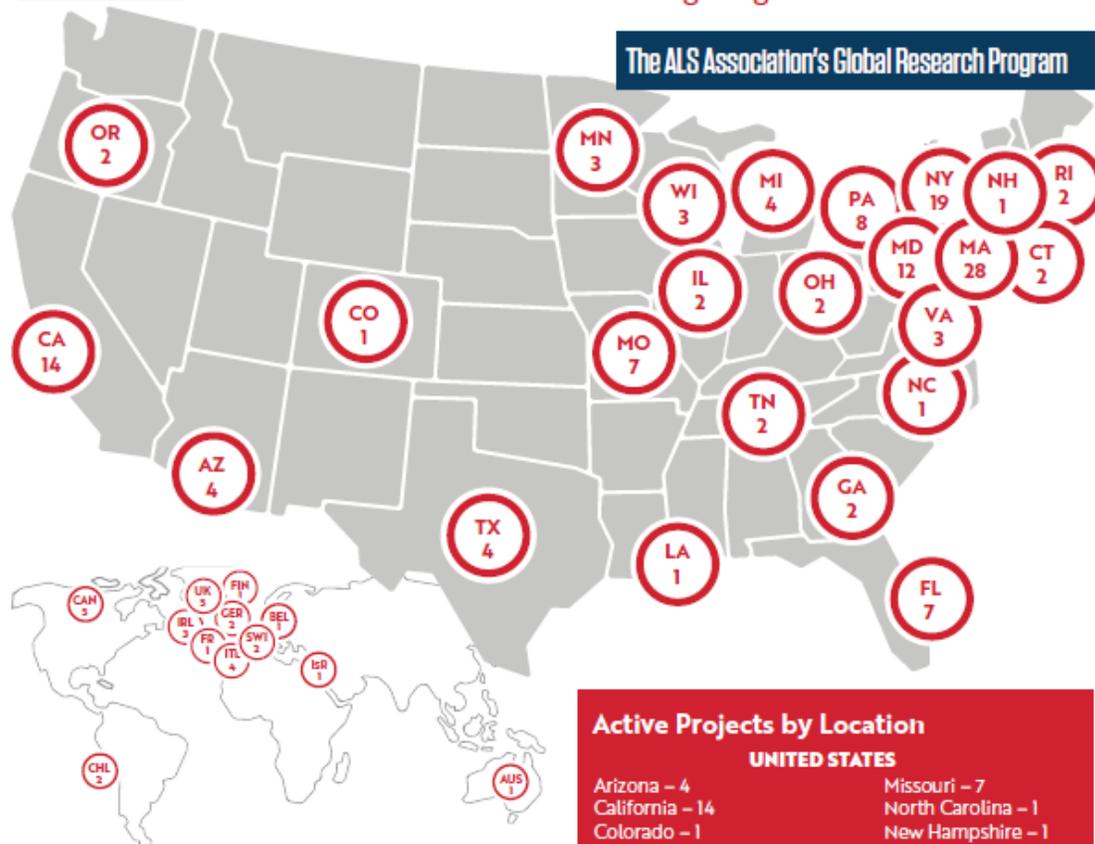
- Waive the five-month waiting period for social security disability insurance
- Expand access to home infusion for Medicare beneficiaries
- Fairly compensate families of veterans with ALS
- Preserve and increase federal resources for ALS research
 - Double Department of Defense ALS Research Program funding from \$20 to \$40 million
 - \$10 million to continue the Center for Disease Control and Prevention's National ALS Registry/Biorepository
 - \$44.7 billion for the National Institutes of Health to increase investments in ALS research
- Expand access to telemedicine and telehealth
- Represent people living with ALS on access to health care, drugs, and therapies

“On December 22, the ALS Disability Insurance Access Act became law. The law became effective immediately on December 23, waiving the five-month waiting period before people with ALS can access Social Security Disability Insurance (SSDI) and Medicare benefits. This law was the result of four years of advocacy by the entire ALS community. Since the law was passed, The ALS Association has met with the Social Security Administration to ensure applications for SSDI are quickly processed and benefits start immediately for people with ALS.”

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 project we cannot directly support, and invest in the people and infrastructure needed to make ALS research efficient and effective.

ALS ASSOCIATION **CURRENT PROJECTS** The ALS Association is Accelerating Progress Toward Treatments



162 Active Research Projects

In an effort to accelerate progress toward finding treatments and a cure for ALS, as of 02/01/2021, The ALS Association is currently funding 162 active research projects total. There are 134 within the United States.

PALS STORIES

Bob & Anita McDonald

"My husband, Bob McDonald was diagnosed with ALS in 2008 in New Jersey. We received medical services from the ALS Clinic at Drexel University until we relocated back to Tucson in 2012.

Bob and I learned about the ALS Walk when we began attending the pALS support group, sponsored by the ALS Association Arizona Chapter, in 2013. We spent so much time that first year just adjusting to being back in Arizona, and dealing with other issues like home modifications and equipment. However, by 2014 we were very much committed to participating. We had not only experienced personally the importance of funding for the ALS Association but how important it was to others living with ALS as well.

Bob and I were not a very creative when it came to naming our team. We had no family here and had not developed a cadre of friends with whom we could seek advice or ideas from for our Team name so we kept it simple; Team McDonald. Our Team slogan "Stepping up for those who can't" was Bob's brilliant idea; I say that because he was a pretty witty guy. So, while we have changed t-shirt colors a couple of times and the graphic design, we have not changed that central theme that Bob articulated.

While most of our friends and all of our family lived elsewhere, we did not let that stop us from inviting them to be a part of Team McDonald. Locally, I had been a member of the Catalina Rotary Club for many years and members of the Club stepped up and essentially became my family.

At our first walk I believe we had nine people including my daughter who came from Denver, one of Bob's Caregivers and her family, and to Bob's great delight and surprise, a former coworker from New Jersey. This was a special moment for Bob. He was unaware that his friend and his wife had moved from New Jersey to Las Cruces, New Mexico. When I sent out an email notice about the Walk seeking donations and participation, they responded that they would be attending. His friend drove in the night before the Walk, attended the Walk and spent the afternoon with us visiting over lunch. Bob was so happy to spend time with his friend and as they left, it was one of the few times that I saw Bob tear up. They drove back to Las Cruces the next morning.

I know that all who support Team McDonald do so in honor of Bob knowing he would be pleased we are helping others living with ALS and their families like he was helped. Bob was amazed to see the number of people participating in the Walk. Although he was tired after each one, the event made him hopeful that one day we would find a cure and indeed #DefeatALSAZ!"

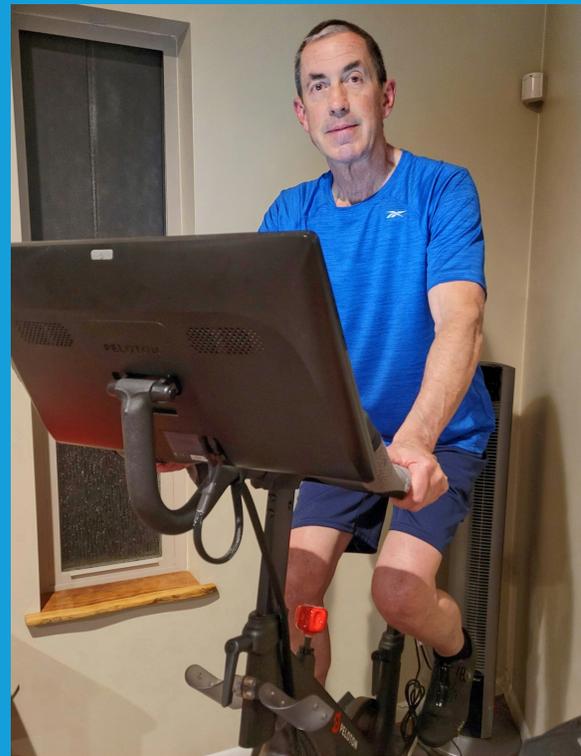


PALS STORIES

Kevin Gallagher

Kevin Gallagher was a champion for our new event, the Ride to Defeat ALS, far before its inception. In the fall of 2020, Kevin suggested that we partner with Peloton and other cyclists to raise awareness and funds for ALS. This idea soon evolved into our first-ever Ride to Defeat ALS! Kevin was determined to make this ride a success and said that since “the max for donations was 100 miles, [he] thought [he] would try to make a century for the cause and also as a present to [himself] for [his] 65th birthday.” Kevin exceeded his goal and rode 100.37 miles in support of ALS families!

"As someone with PLS (Primary Lateral Sclerosis), I have direct experience with the incredible services and support that the ALS Association Arizona Chapter provides to people with motor neuron disease. From the multidisciplinary health care providers in the clinics to the care coordinators and administrative staff, I have never encountered a more caring, compassionate, and dedicated group of people united in a common cause.



It was heartbreaking to finally admit I could no longer ride outside and had to sell my bikes. The Peloton has been a godsend since once I manage to clip in I can feel ‘normal’ again and enjoy riding. I didn't know if I could manage to achieve the 100 miles, but it was a great feeling to make it.

It was truly a privilege to be able to ride in this event to support the ALS Association and help them in their commitment to defeat ALS."



WALK TO DEFEAT ALS

\$436,521



BITE NITE

\$180,858



THIRD-PARTY EVENTS

\$64,064

SCOTTSDALE WALK TO DEFEAT ALS



\$375,850 RAISED • 472 PARTICIPANTS • 101 TEAMS

TOP TEAMS

- | | |
|--|--|
| 1. Team Vanessa \$144,300 | 6. Hom's Homies \$11,622 |
| 2. Keniston's ALStars \$23,151 | 7. Peggy's Posse \$10,170 |
| 3. Stormin Norman's Rockin Crew \$21,230 | 8. Chase the Cure for ALS \$8,890 |
| 4. Iron Horses \$15,529 | 9. Team Proudfoot \$8,320 |
| 5. Ray's Rebels Against ALS \$14,487 | 10. Westbrook Warriors Against ALS \$7,500 |

TUCSON WALK TO DEFEAT ALS



\$ 60,670 RAISED • 187 PARTICIPANTS • 28 TEAMS

TOP TEAMS

1. Lady Baba's Band of Beauties \$17,175
2. Team McDonald \$10,210
3. Kay's Shining Stars \$7,015
4. Doreen's Team \$5,500
5. RPKinkade \$4,780

WALK YOUR WAY

Since we couldn't gather in person for the Walk to Defeat ALS due to Covid-19 restrictions, we encouraged everyone to "Walk Your Way" safely in their own neighborhoods. Walk teams all over Arizona and the country watched our virtual program on Facebook on the day of the walk and celebrated with their families.



OUR STAFF



TARYN NORLEY
Executive Director



ANGIE TIGGES
Director of Special Events



AMY FRANK
Director of Care Services



RONDO SMITH
Respiratory Therapist



MA'AYAN MAOZ
Care Services Coordinator



AMBER MONTANEZ
Care Services Coordinator



BEKAH BARAJAS
Office Manager



HANNAH TERHAAR
Development Coordinator



MALLORY AUTREY
Development &
Operations Assistant

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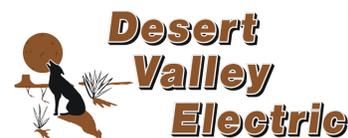
Robert Meyncke
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Bonneville International

THANK YOU SPONSORS!

IN 2020, THESE CORPORATE SPONSORS RAISED OVER \$140,000 FOR OUR CHAPTER.



**UPCOMING EVENTS
IN 2021**

BITE NITE
OCTOBER 30

VISIT WWW.BITENITE.ORG TO LEARN MORE



NOVEMBER 13TH - TUCSON
NOVEMBER 20TH - SCOTTSDALE

VISIT WWW.WALKTODEFEATALS.ORG TO START YOUR WALK TEAM!

GET INVOLVED!

There are so many ways to get involved with our organization and help Arizona families living with ALS. We would love to hear from you! Feel free to email us with any interest or questions.

Advocacy amber@alsaz.org

Volunteer mallory@alsaz.org

Walk to Defeat ALS angie@alsaz.org

Bite Nite

3rd Party Events

Sponsorships hannah@alsaz.org



STAY UP TO DATE BY FOLLOWING US ON SOCIAL MEDIA



@ALSArizona



@ALSArizona



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#DefeatALSAZ

IN LOVING MEMORY

2/1/20120- 1/31/2021

Mary Abell	David Dennis	Walter Kirn	Charles Mulhern	Maria Sevada
Wesley Alexander	Eileen Dittmar	Larry Kistler	Thomas Mulhern	Teresa Shaffer
Anwarshah Anwary	William Dowling	Jeane Knudsvig	James Nix	Steven Siegel
Victoria Armstrong	Helen Ducharme	Stephen Kore	Patricia Norton	Renee Smith
Richard Aubuchon	Jeffrey Duncan	Marsha Kramer	Roberta Olson	David Snyder
Barbara Bass	George Elliott	Mark Krebs	Ashley Olsson	Claudette Spain
Darlin Baumunk	Diana Francis	Warren Kuetemeyer	Lisa Paleo	Linda Spellman
Hilal Al Bayati	Brent Gabrielsen	Norma Lais	Sandra Parrish	Mary Spethman
Judy Benjamin-Raley	Scott Galler	Tammy Lake	Marie Pedersen	Jerry Stahlman
Walter Bernaitis	Dan Garrison	Lisa Larson	Benjamin Pittman	Rosa Stedman
Michael Berry	Homer George	Cynthia Lawrence	Brian Pollock	Roger Stone
Irby Blakesley	Ruth Godlove	Simon Le	Jerry Porter	Marianne Stoner
Loreen Blanchard	Greg Gonzales	Theresa Lee	Debra Pulos	James Taylor
Michael Boggs	Virgil Good	Terry Lehan	Ken Ralston	Michael Teske
Dawn Bostwick	Laurie Goodin	Brenda Lewis	Hector Ramirez	Ronald Thomas
Dawn Boushelle	Michael Haley	Jacqueline MacDonald	Eddie Ray	Joyce Tominaga
Leslie Brisbois	Linda Hamala	Belinda Marcotte	Gary Reber	Lewis Trujillo
William Brown	James Harris	Glen Martin	Suzanne Renaud	Mark Turley
Alfred Bush	Byron Haynes	Angela Martinez	Leo Rhein	Dawn Valanas-Moser
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Andrew Denard	Sherrie King	Shannon Motta	Troy Schmick	Baron Wolman
	Richard Kinkade	Linda Moyer	Allan Schwister	Robert Word



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