

2020 IMPACT REPORT

Photo by Jiovana Photography

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 APRIL & SUZANNE

Dear friends,

When our fiscal year ended on January 31, 2020 and we looked back on all that had been accomplished to help people with ALS in Nevada, we couldn't help but smile. In June of 2014, April was hired as an interim executive director to help lead a small organization called ALS of Nevada. The staff consisted of her and one part-time care services person and the organization was led by a board of directors that were determined to serve every Nevadan with ALS with the limited resources we had. In July of 2014, a social media phenomenon happened and our little organization was swept up in the whirlwind that was the Ice Bucket Challenge. This was the beginning of our transformation from ALS of Nevada to The ALS Association Nevada Chapter.

By 2019, we had grown to a staff of five – two Care Services staff, one Events staff, an Administrative Assistant, and our executive director. Our service population had grown to over 100 people with ALS and their families. Our service offerings grew and we expanded to four loan closets, five monthly support groups, respite for both northern and southern Nevada and we added the TeamCurtis4aCure Transportation Program. This annual report, our first since becoming a Chapter of The ALS Association, will highlight for you many of the successes we've had and the impact this organization has had on Nevadans with ALS.

Our staff, board members and volunteers work hard every day to ensure that we are here to serve every person with ALS whom we can. But this is nothing compared to what people with ALS and their families, friends and caregivers go through day after day. The people highlighted in this report represent a small sample of the many reasons we are encouraged to work hard day in and day out, and none of this would be possible without the incredible community support we receive.

Sincerely,

Suzanne Oetjen

Suzanne Oetjen
Chair



Sincerely,

April Mastroluca

April Mastroluca
Executive Director



YOUR IMPACT IN NEVADA

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



\$388,070

total spent on programs and services for PALS and their caregivers



59

new PALS served

122

home visits provided



2,884

hours of respite care provided



137

PALS appointments at multidisciplinary ALS clinics



ALS support group meetings



days traveled by PALS through transportation program

169

people attended ALS support groups



35

transportation trips provided to PALS

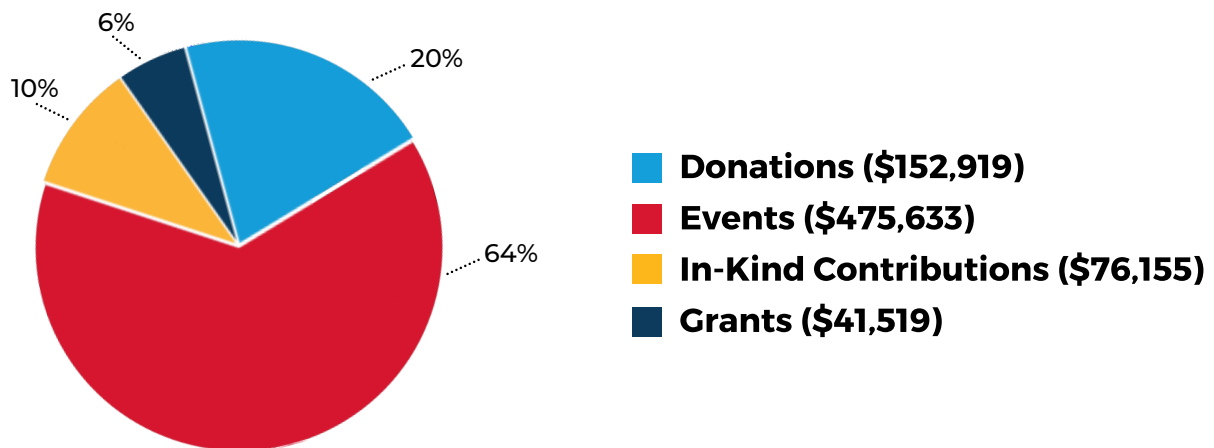
THANK YOU!

FINANCIALS

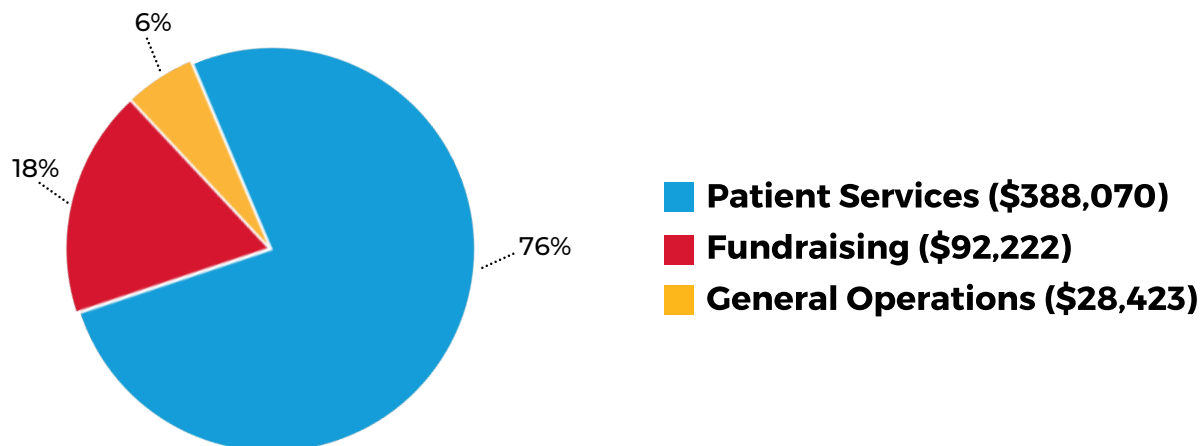
As a 501(c)(3) organization, we depend upon the generosity of individuals, corporations, foundations, grants, and community partners who provide us with tax-deductible contributions so that we may support our ALS community.

Out of every dollar donated, 76 cents goes to provide free services and programs to Nevadans with ALS.

Revenue



Expenses



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, mental health professional, and an ALS Association Chapter liaison.

The ALS Association Nevada Chapter is proud to offer three different locations for ALS multidisciplinary clinics throughout the state: Roseman University ALS Clinic in Las Vegas, directed by Dr. David Ginsburg; Saint Mary's Medical Group Clinic in Reno, directed by Dr. Timothy Louie; and Las Vegas Clinic ALS Clinic, directed by Dr. Jonathan McKinnon. ALS clinics are operated monthly and the Nevada Chapter provides support to the clinic at no cost to the patient.

DR. DAVID GINSBURG

Dr. Ginsburg (standing far left) received his Doctor of Medicine degree from University of Pittsburg in 1988. Later, he completed his residency in neurology at Los Angeles County-USC Medical Center and later a fellowship in clinical neurophysiology. This provided him with an extensive background in neurodiagnostic testing with EEG and EMG, and exposure to a large number of patients with neuromuscular disease. Dr. Ginsburg is board-certified by the American Board of Neurology and is a diplomat of the American Board of Psychiatry and Neurology.



DR. TIMOTHY LOUIE

Dr. Louie attended medical school at Loyola University of Chicago in Chicago, IL and completed his neurology residency at the University of California, Irvine in Orange, CA. Additionally, he specialized in neuromuscular diseases and electromyography (EMG) during his fellowship at the University of Utah in Salt Lake City. Prior to joining Saint Mary's, Dr. Louie served as director of Northern Nevada Muscular Dystrophy Association and has practiced neurology in northern Nevada for over fifteen years. Dr. Louie is board-certified by the American Board of Psychiatry and Neurology.

DR. JONATHAN MCKINNON

Dr. McKinnon earned his Doctor of Medicine degree from the Ohio State University. He then completed his residency in neurology and a fellowship in clinical neurophysiology at the Mayo Clinic in Arizona. Following this, Dr. McKinnon completed a fellowship in clinical neuromuscular medicine at the University of California, Irvine. Dr. McKinnon is a board-certified neurologist and has a specialty board certification in neuromuscular medicine.

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



PATIENT SERVICES COORDINATOR

Social worker and/or ALS Association representative and liaison to provide a patient with ongoing support and resources to fulfill clinic recommendations

THANK YOU CLINICIANS!

Our multidisciplinary ALS clinics wouldn't be possible without the dedicated teams of healthcare professionals and the exceptional care they provide each month to people living with ALS.

David Ginsburg, MD

Neurologist

Timothy Louie, MD

Neurologist

Jonathan McKinnon, MD

Neurologist

Jenn Bithell, ATP

Assistive Technology Specialist

Lisa Boughner, PT

Physical Therapist

Bobby Davis, SW

Social Worker

Suzanne Davis-Twasta

Care Services Coordinator

Ben Erskine, OT

Occupational Therapist

Karen Fletcher, PT, DPT

Physical Therapist

Geri Lynn Grossman, RD

Dietitian

Elden Henry-Pottinger, BOCO

Orthotist

John Howitt, RT

Respiratory Therapist

Cristie Huennekens, MRD

Dietitian

Julia Humphrey, ATP

Assistive Technology Specialist

Taryn Joyner

Care Services Coordinator

Lavenia McCoy, MA

Medical Assistant

Nellie Milner, OT

Occupational Therapist

Tiffany Miske, SLP

Speech Language Pathologist

Randy Morris, ATP

Assistive Technology Specialist

Jennifer Nash, PT

Physical Therapist

Moriah Orosco, MA

Medical Assistant

Fatima Patterson, SLP

Speech Language Pathologist

Skylar Post, ATP

Assistive Technology Specialist

Karen Sanders, RT

Respiratory Therapist

Laura Tolotti, SLP

Speech Language Pathologist

PALS ON THE MOVE WITH



Photo by Jiovana Photography

TeamCurtis4aCure was created

after Chris Curtis, a Las Vegas native, was diagnosed with Amyotrophic Lateral Sclerosis (ALS) in 2014. Chris was a prominent attorney and an active outdoors man prior to the diagnosis, enjoying activities including off-road racing, running, hiking and climbing, mountain biking, backpacking, skiing, hunting, and fishing. Now that Chris can no longer do these activities, he focuses his energy on enjoying life with family and friends, advocating for ALS, and living by TeamCurtis4aCure's guiding principal: #DoWhatYouCanDo.

In 2018, The ALS Association Nevada Chapter established the TeamCurtis4aCure Transportation Program through a grant from the Christopher Reeve Foundation and seed money donated by TeamCurtis4aCure to provide a much-needed resource for people living with ALS. Many PALS do not have access to wheelchair-accessible transportation and thus become trapped in their homes. The TeamCurtis4aCure Transportation Program provides PALS the use of free, wheelchair-accessible transportation on demand. PALS can use the service for medical and non-medical trips including monthly multidisciplinary ALS clinics, restaurant visits, museum trips, art and music events, movies, sporting events, and family events. Here are just a few stories from the many trips PALS were able to take in 2019 thanks to the TeamCurtis4aCure Transportation Program:

Program Achievements

- After Carol was diagnosed with ALS, she moved to Mesquite so her mother could care for her. She had progressed to the point where she needed to be moved to a care facility in Las Vegas, but her 87-year-old mother couldn't drive to Las Vegas to see her daughter. The TeamCurtis4aCure Transportation Program was able to pay for a shuttle to bring her to Las Vegas and a Lyft to take her to the care facility to visit her daughter. Carol's mother was able to visit her twice a month until she passed.
- Brian was able to take a 2-week trip to California and create great memories with his parents because they were able to rent a van through the TeamCurtis4aCure Transportation Program. This was the first time Brian had been able to travel since his diagnosis in 2013.
- Peggy was able to go see her granddaughter perform in her first ballet recital because her husband obtained a wheelchair-accessible van with the help of the TeamCurtis4aCure Transportation Program. Sadly, Peggy died just 66 days later.
- Daniel wanted to see his daughter get married, but the wedding was going to be in California. The TeamCurtis4aCure Transportation Program provided a rental van to allow Daniel and his caregiver the ability to attend the ceremony and celebrate with family.

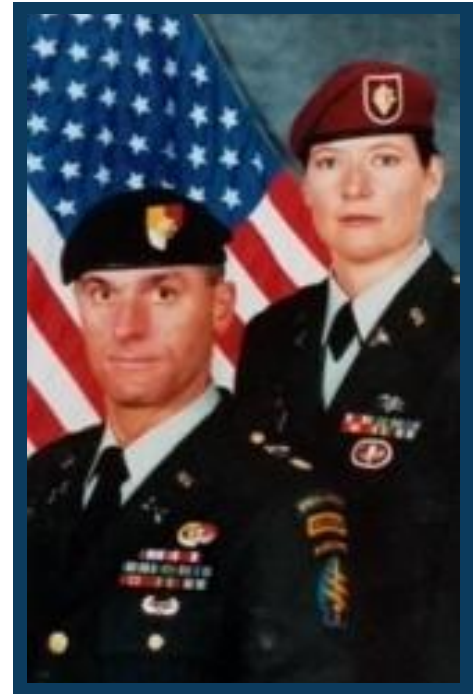
#DoWhatYouCanDo

PALS STORIES

COL. DINO ROTH

Told by his wife, Tammy

Dino was a Special Forces Colonel who served his country for 30 years. He retired in 2007 bought an RV and traveled the country. He and his wife bought a home in Colorado and skied in Summit County every week during season. He hiked to the top of three 14'ers meaning the summit was over 14,000 feet in elevation. In 2010 he noticed stiffness in his left arm that grew to weakness. He was diagnosed with a variety of conditions over the years but in September 2016 he was diagnosed with ALS at the VA hospital in Golden, Colorado. In February 2017 that was confirmed at the Mayo Clinic in Scottsdale, AZ.



Col. Dino Roth & Lt. Col. Tammy Roth

Dino remained mobile with the help of a walking stick, then a walker and finally a wheelchair in November 2018. His personal goal was to not use the chair until after Christmas, he came close. Dino remained in the family home with care from his spouse and homecare aides. With assistance he was able to take a shower and watch TV in the wheelchair, even on his last day August 30, 2019.

Dino refused any extra measures like oxygen, feeding tube or even c-pap. He took Riluzole for 3 years and never tried Radicava. Like so many affected by ALS he was fit before it struck and kept up the fight until the very last day. His life changed dramatically but he did not. ALS stole his body but never his spirit or sense of humor. This warrior fought the good fight!



PALS STORIES

TAMMY MARCONI

Told in her words

I was a casino cocktail waitress at one of the most beautiful hotels in Las Vegas...The Bellagio! I opened the hotel in 1998 and worked there for almost 20 years. I did pilates and hot yoga and had no other health problems for 49 years of my life.

Shortly after my mother's death in 2016 I started noticing shortness of breath when I climbed the stairs...they said it was asthma. I started having severe pain in my left foot, upon returning to work after month long leave of absence, following my mother's death. They said it was arthritis. I started feeling slightly weaker at work...my job required walking all night and carrying a heavy tray full of cocktails all night, but it was not severe enough to cause too much alarm. I was, after all, almost 50. I chalked it up to just getting older.



Tammy with her husband, Steve

Then I started to notice very slight problems with my speech. I was having trouble pronouncing certain sounds. I thought it was sinuses and went to 2 ENT specialists. I also had an endoscopy because I noticed changes in my swallowing. They all suggested I see a neurologist. The process took quite awhile, but I was finally diagnosed with ALS almost 18 months later, in May of 2018.

By the time I was diagnosed, my speech had deteriorated to the point that I could no longer perform my job because I could no longer speak properly. Over the last 2 years, I have completely lost my ability to speak, can only swallow soft mushy foods, use a bipap machine to help me breathe for several hours a day, and am losing my ability to walk. I use a walker or a motorized scooter to get around. I am also losing strength and dexterity in my hands. I have been on Radicava infusions (which are said to slow the progression) for about 20 months, now. I have a wonderful husband who is very loving, supportive, and helpful. Since my diagnosis, we have taken many fun trips...to Lake Tahoe, San Francisco, Hawaii, a road trip down the California coast, Washington D.C., and Zion National Park! We try not to think too far ahead and just enjoy each day for what it holds, and stay hopeful and positive for a cure!



Photo by Jiovana Photography

SUPPORT GROUPS

We're proud to offer monthly support groups in areas throughout Nevada, including Reno, Carson City, Henderson, and Summerlin. Support group meetings can be an educational gathering, a safe place to express emotions, or a forum to share experiences and information. PALS, caregivers, family, and friends are welcome to attend to give and take the wisdom and experience that comes from living with a devastating illness.

On learning of his ALS diagnosis and attending our Henderson support group, Brian said:

"After the full spectrum of emotions you would expect, I realized that I could basically either give up and withdraw or fight and make the most of the time I have left...The support groups not only help to show you're not alone but are a great place to get information that you might not otherwise easily find on your own. I think one of the reasons I'm still here going on 6 years is because I've had people to lean on including the ALS Association staff, as well as the people I've met at the support group. I know that dealing with this disease, even small things can be an ordeal, but I really do believe that you'll find attending the support group beneficial."

Bob and Helen said of our Carson City support group:

"...The bottom line for us is that just being with other ALS patients and their families provides the opportunity to hear what others are experiencing. Even though we haven't had the particular experience yet, it helps to get a heads-up about what may be coming. It helps to reduce the 'unknowns'. We also find that presentations by different providers – wheelchairs, text-to-speech devices, ventilators, physical therapists, speech pathologists, etc – provide insights into what kind of help is out there. Most of us are in this type of a situation for the first time and learning what kind of help is out there on your own is a daunting task: you don't know what you don't know!"

GLOBAL IMPACT

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.



169

ACTIVE RESEARCH
PROJECTS
AS OF 2/3/2020

11

NEW ALS GENES
IDENTIFIED SINCE
2014 ALS ICE BUCKET
CHALLENGE

9

NEW GLOBAL
STRATEGIC INITIATIVES
LAUNCHED OR
SUPPORTED

33+

ALS DRUG TRIALS

64+

NEW GLOBAL
RESEARCH PROJECTS
AWARDED

ALS ADVOCATES

Every year, hundreds of ALS Advocates come to Washington, D.C. to learn about the latest ALS research, network, and visit Capitol Hill to share their stories with members of Congress and gain legislative victories. The 2019 National ALS Advocacy Conference focused on educating, 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.

ALS Staff members Lisa Tomlin-Kurr (standing left) and Taryn Joyner (standing far right) accompanied Nevada ALS Advocates, Tammy Marconi (seated left) and Leah Borden (seated right) along with their caregivers as they met with Senator Catherine Cortez-Masto, Senator Jacky Rosen, Representative Mark Amodei, Representative Steven Horsford, Representative Susie Lee, and Representative Dina Titus to discuss the lead ALS Advocacy initiatives for 2019. These initiatives included:



- Waiving the 5-month waiting period for Social Security Disability Insurance for PALS
- Preserving and increasing federal resources for ALS research, such as the ALS Research Program at the Department of Defense, the National ALS Registry & Biorepository at the Centers for Disease Control, and ALS research at the National Institute of Neurological Disorders & Stroke and other Institutes at the National Institutes of Health
- Improving access to home health services for people with ALS
- Representing people living with ALS on access to health care and medications

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.



DRIVE TO DEFEAT ALS

\$30,832 raised



FOOD IS ART

\$216,188 raised



TEAMCURTIS4ACURE TRANSPORTATION PROGRAM

\$77,250 raised

RENO WALK TO DEFEAT ALS®



\$52,105 RAISED • 350 WALKERS • 479 DONORS

TOP TEAMS



- | | |
|-----------------------------------------|--------------------------------------------------|
| 1. TeamCurtis4aCure - \$9,886 | 6. Never Give Up - \$2,525 |
| 2. Walkie Talkies Against ALS - \$6,325 | 7. Team Whitfield - \$1,810 |
| 3. Emme's Team - \$3,350 | 8. The Noble Motor Units of St. Mary's - \$1,465 |
| 4. Team DJ - \$3,000 | 9. Feet for Follett - \$1,175 |
| 5. Sandy's ALStars - \$2,720 | 10. FreddysWarriors - \$1,110 |

SOUTHERN NEVADA WALK TO DEFEAT ALS®



Photo by Jiovana Photography

\$103,966 RAISED • 802 WALKERS • 917 DONORS

TOP TEAMS



- | | |
|-------------------------------------------------------|-------------------------------------|
| 1. TeamCurtis4aCure - \$17,435 | 6. Team Dragon - \$3,420 |
| 2. Laird's Noble Racers - Henderson Chamber - \$7,470 | 7. Roxie Strong - \$2,919 |
| 3. Team Sunflowers - \$5,058 | 8. Tony's Team - \$2,880 |
| 4. Team Sexton - \$4,150 | 9. No whining, only WINE! - \$2,625 |
| 5. Team Janiece / Anderson Dairy - \$3,425 | 10. Lucky Stars - \$2,489 |

OUR STAFF



April Mastroluca
Executive Director



Taryn Joyner
Care Services Coordinator



Suzanne Davis-Twasta
Care Services Coordinator



Lisa Tomlin-Kurr
Special Events Manager



Kelsey Stasi
Office Administrator
& Grants Coordinator

BOARD OF DIRECTORS

2017-2019

Suzanne Oetjen
Chair
Renown Health

Bill Paul
Vice Chair
*Atlas Enterprise
Software*

John Houston
Secretary/Treasurer
*Flying A Information
Resources*

Dave Ray
Past President
GRN Vision

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Golden Entertainment

Larry Brown
*Clark County
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Kristopher Dahir
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Ashley Ferrel, Esq.
Simon Law

Linda Hollis
Rail City

John Howitt
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Medical*

Georges Maalouf
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Marisa Martino
ATM HOSP/TPR

Maxine Paul
NuMotion

Jake Ramatici
*LP Insurance
Services*

THANK YOU SPONSORS!



UPCOMING EVENTS IN 2020

MAY 2

**Reno/Sparks
Walk to Defeat ALS®**
Virtual Walk



MAY 31 - JUNE 2

**National Advocacy
Conference**
Virtual Conference



SEPTEMBER 26

Food is Art Gala
Virtual Gala



OCTOBER 19

**Drive to Defeat ALS
Golf Tournament**
The Legacy Golf Club



NOVEMBER 8

**Southern Nevada
Walk to Defeat ALS®**
Virtual Walk



IN LOVING MEMORY

February 1, 2019 - February 1, 2020

William Babb
Salvatori Balistreri
Gladys Bejarano
Odisey Brabham
Myron Branning
Johannes Breedt
Karen Chalhoub
Theodore Chikowski
Addie Coggs
Francis Corres
Cleo Curd
Dale Etheridge
Daniel Fragoso
Mary Guitrau-
Sanford
Tony Haney
Mary Henley
Kathleen Hoff
Crisostomo Ibarra
Salvador Juarez
Jerry Lands
Larry Manning
Francine Manuel
Caridad McKay
Victor Milewski

Roy Moore
David Ortiz
Barbara Owens
Theodore Porfilio
Robert Priante
Myrna Quitazol
Gregorio Ramirez
Dino Roth
Blanca Sanchez
Jack Segel
Michael Sexton
Robert Sosnowski
James Spear
Kimberley Squires
Yolanda Stibor
Peggy Svenonius
Darcy Tyrrell
Mattie Wafer
Marshall
Weatherly
Carol West-Sieme
Margaret Willer
Jim Williams
Leo Yabut
Helen Zeisloft



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