

ALS Arizona

FOUNDATION OF SERVICES AND SUPPORT



February 2025 Newsletter

ALS Arizona Research Day!

Friday February 28th
10am - 3pm

360 E Coronado Rd. Ste 140 Phoenix, AZ 85004



Research Presentation

Learn about exciting new findings and ongoing studies!



Coffee Bar

Enjoy complimentary coffee while networking with researchers!



DIY Trucker Hat

Create your own custom trucker hat!



Participate in Research

Be part of real research studies happening on site!

****If interested in participating; please contact us so we can schedule**

Join us for a day of discovery!



Email deboni@alsaz.org to RSVP!

**ALS
Arizona**

Click [HERE](#) to RSVP!

ALS EDUCATION SERIES

FIVE WISHES

Join us for Our First ALS Education Session of the Year:

End-of-Life Planning with Five Wishes

Our Director of Education and Family Resources, Janie Dalrymple, will guide you through Five Wishes, an important tool for planning for your care and communicating your wishes clearly to loved ones.

What to Expect:

- Understanding Five Wishes: Learn how this simple yet comprehensive document can empower you to decide about your care, comfort, and dignity.
- Benefits of Early Planning: Discover how proactive planning can relieve stress for you and your family and ensure your wishes are respected.

Whether you're newly diagnosed or supporting a loved one, this session will provide valuable knowledge to help guide you through an often difficult but essential process.

Feb. 6th from 10 - 12

BHHS Legacy Conference Room, 360 E. Coronado Rd, PHX 85004



[Register Here Today!](#)



ALS Arizona
Member of ALS United

CAREGIVER SKILLS TRAINING
Hoyer Lift, Transfers, Range of Motion, & more!

02.14.25
9:30AM - 3:00PM

ENCOMPASS REHAB
13460 N 67th Ave, Phoenix 85304
Lunch Provided

Scan QR Code or email debarri@alsaz.org to Register Today!



ALS Arizona
Member of ALS United

CAREGIVER SKILLS TRAINING
Hoyer Lift, Transfers, Range of Motion, & more!

03.21.25
11 AM - 4:00PM

ENCOMPASS REHAB
2650 N Wyatt Dr, Tucson 85712

Scan QR Code or email debarri@alsaz.org to Register Today!

Caregiver Training Day: Empowering You with Knowledge and Skills

Whether you're a primary caregiver or a support person for a loved one with ALS, this training day is an invaluable opportunity to gain practical knowledge and skills.

What You'll Learn:

- **Safe Transfers:** Learn how to use equipment like Hoyer lifts to perform safe and comfortable transfers for your loved one.
- **Range of Motion Exercises:** Discover techniques to maintain mobility and improve quality of life through simple, effective exercises.
- **Communication Options:** Explore alternative communication tools and strategies to stay connected with your loved one as their needs evolve.
- **And Much More!:** We'll cover additional essential caregiving topics for providing high-quality, compassionate care.

Please Note: This training session is designed specifically for caregivers only.

[Click Here to RSVP for Phoenix Caregiver Skills - Feb. 14th](#)

[Click Here to RSVP for Tucson Caregiver Skills - March 21st](#)



Join us in welcoming Robin H. Melillo!

Robin is an occupational therapy student at Northern Arizona University, we are honored to have her complete her doctoral capstone project with ALS Arizona. Before returning to graduate school, Robin worked as a certified physical therapist assistant for many years. Robin is excited to be part of the ALS Arizona community and looks forward to connecting with you over the next 12 weeks.

ALS ARIZONA SUPPORT GROUPS

Monthly support groups provide opportunities for attendees to share personal experiences and learn strategies for preserving the independence and quality of life for both people with ALS (pALS) and their caregivers.

Join us in person or online as noted below

PALS SUPPORT GROUP ALL ARE WELCOME!

Statewide - Virtual

2nd Tuesday 6:00-7:30pm
Zoom meeting ID: 957 2816 7840
Passcode: 785624

Central AZ - In Person Only

2nd Tuesday 1:00-3:00pm
BHHS Legacy Conference Room
360 E Coronado Rd Phoenix, 85004

Tucson - In Person Only

4th Monday 1:00-3:00pm
Our Saviour's Lutheran Church
1200 N Campbell Ave Tucson, AZ 85719

Northern AZ - In Person Only

4th Monday 1:00-3:00pm
Starting Point Church
3106 Gateway Blvd Prescott, AZ 86303

Join Virtual meetings
from your computer, tablet, or smartphone
by scanning the QR code

CAREGIVER SUPPORT GROUP

Statewide - Virtual

3rd Tuesday 1:00-3:00pm
Zoom meeting ID: 945 4494 4731
Passcode: 009354

Central AZ - In Person Only

2nd Tuesday 1:00-3:00pm
ALS Arizona Conference Room
360 E Coronado Rd Phoenix, 85004

Tucson - In Person Only

3rd Wednesday 1:00-3:00pm
Our Saviour's Lutheran Church
1200 N Campbell Ave Tucson, 85719

Statewide pALS
Support Group



Statewide Caregiver
Support Group



[Click Here to join
Statewide pALS
Support Group - Feb.
11th @ 6 pm](#)

[Click Here to join
Statewide cALS
Support Group - Feb.
18th @ 1 pm](#)



ASK THE NURSE

JANIE DALRYMPLE

BRING YOUR **ALS QUESTIONS** AND JOIN US
VIA ZOOM EVERY 4TH TUESDAY @ 10 AM

MEETING ID: 943 3205 4281
PASSCODE: 554993

**ALS
Arizona**

Email questions to deboni@alsaz.org

The graphic features a smiling woman with blonde hair and glasses, wearing a grey off-the-shoulder top. The background is light blue with white plus signs and a grid of dots.

[Click Here to join Ask
the Nurse - Feb. 25th @
10 am](#)

ADVOCACY



Thank you to Senator Lela Alston for meeting with our ALS Arizona Advocacy Steering Committee members this week.

We appreciate her support in advocating for changes to expand access to Medigap coverage for individuals with ALS under 65.

Email deboni@alsaz.org to learn more or get involved in this effort.

ALS Arizona



ALS UNITED 2025 ADVOCACY PRIORITIES

Based on comprehensive community input, ALS United has identified three critical priority areas for 2025:



EXPAND RESEARCH & TRIAL ACCESS

- Increase research funding opportunities
- Reduce barriers to clinical trial participation
- Support innovative treatment approaches



ENHANCE FINANCIAL SUPPORT SYSTEMS

- Advance caregiver support initiatives
- Promote tax relief for ALS-related expenses
- Support home modification assistance



IMPROVE HEALTHCARE ACCESS & COVERAGE

- Address provider availability gaps
 - Support transportation solutions
- Expand coverage for treatments

OUR APPROACH:

- Data-driven decision making
- Collaborative advocacy
- Flexible response to emerging legislation
- Support for both federal and state initiatives



Want to learn more about how you can support our state and federal advocacy efforts? Sign up [HERE](#) for more information or email deboni@alsaz.org

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Member of ALS United

SAVE THE DATE

ALS ARIZONA STATE ADVOCACY DAY
FRIDAY, MAY 9TH

EDUCATION CORNER

There are always chances to learn more about advances in ALS research, ways to increase quality of life, and to hear from experts in the field! Below are some opportunities for you to explore:

Exposomics and epigenetic ALS insights: How exposures alter ALS risk and progression

Dr. Goutman from the Northeast Amyotrophic Lateral Sclerosis (NEALS) to discuss the role of environmental exposures on ALS based on studies conducted through the University of Michigan and the Pranger ALS Clinic at Michigan Medicine. Register [here](#).

Expanded Access Programs in ALS: What We Have Learned, and Where We Go from Here

In this webinar, Drs. Andrews, Babu, and Bedlack will explain what Expanded Access Programs (EAPs) are and how they differ from other pathways by which people living with ALS can access experimental products. They will review what we have learned from recent EAPs, what is happening with the current ones, and where they hope to see EAPs go in the future. They will highlight reliable places to find more information on EAPs. Watch the webinar [here](#).

UPCOMING EVENTS



ALS AWARENESS NIGHT @TUCSON ROADRUNNERS



**RSVP
today!**

[RSVP Here for ALS Awareness Night!](#)

TO RESERVE YOUR TICKETS EMAIL DEBONI OR LINDSEY
DEBONI@ALSAZ.ORG OR LINDSEY@ALSAZ.ORG

2025 Annual Caregiver Summit



**CAREGIVER
COMPASS**

Practical Tips for Navigating Caregiving

**WEDNESDAY, 2/19/25,
9AM-3:45PM**

DESERT WILLOW CONFERENCE
CENTER, PHOENIX, AZ

Agenda At-a-Glance

8:00-9:00am	Registration, Breakfast, Visit Exhibitors
9:00-9:30am	Welcome, Proclamation, Overview of Arizona Family Caregivers Action Plan
9:30-10:00am	Opening Session: Family Caregiving - Finding your True North
10:15-11:15am	Breakout Sessions (Topics include: Taking Care of the Caregiver; Living with Ambiguity; Tips for Hiring In-Home Caregivers; other TBA)
11:15am-12:00pm	Lunch, Visit Exhibitors
12:00-12:30pm	Caregiver Panel
12:30-1:30pm	General Session: Caregiver Legal Rights (Including Consumer Fraud Prevention and Awareness; Guardianship & Conservatorship; Supported Decision-Making)
1:45-2:45pm	Breakout Sessions (Topics include: Role of Palliative and Hospice Care; Responding to Dementia-Related Behavior; How to Create a Self-Care Plan; other TBA)
3:00-3:30pm	Tapping Into Your Inner Joy Through a Calming Guided Meditation and Sound Bath
3:30-3:45pm	Closing Remarks

[Click Here to Register](#)

BITE NITE

EVENT INFORMATION

Bite Nite is a fun, 21 and over event! Here are a few tips that will allow you to enjoy the night.

Bite Nite will be held on Saturday, June 7th at 6:00PM.

Chateau Luxe Event Center
1175 East Lone Cactus Dr. Phoenix, AZ 85024

DRESS ATTIRE - COUNTRY COUTURE

Women - cocktail-length dress or slacks and a blouse
Men - slacks and a button-down dress shirt - jacket and tie optional

EVENT TIMING

6:00PM - 7:15PM - Silent auction, mystery boxes, dining with bites from our partner restaurants and caterers
7:15PM - 8:15PM - Program and live auction
8:15PM - 9:45PM - Live Band/Dancing
10:00PM - Event wrap up

HOTEL INFORMATION

Option 1: As a Bite Nite guest you will receive a -discounted rate of \$89 a night at the Cambria Hotel. Located at 4425 E Irma Ln, Phoenix, AZ

Option 2: JW Marriott Desert Ridge is offering Bite Nite guests discounted rooms of \$284. Located at 5550 East Marriott Drive, Phoenix, AZ.

For more info go to: bitenite.org or <https://bitenitephoenix.givesmart.com>
text bitenitephoenix to 76278

Didn't get all your questions answered? No problem!
Give us a call at 602-297-3800 or email Angie at angie@alsaz.org



Tucson

BITE NITE

Frequently Asked Questions!

EVENT INFORMATION

Bite Nite is a fun, 21 and over event! Here are a few tips that will allow you to enjoy the night.

Bite Nite will be held on Saturday, April 12th 6pm-9pm.

Arizona Sands Club
565 N Cherry Ave, Tucson, AZ 85719

For more info go to: <https://bitenitetucson.givesmart.com>

DRESS ATTIRE

Please wear casual cocktail attire to this event.

EVENT TIMING

Here's a rundown for the event night festivities!

6:00PM - 7:30PM - Silent auction, mystery boxes, dining with bites from our partner restaurants, and caterers
7:30PM - 8:00PM - Program
8:00PM - 9:00PM - Live Music & dancing
9:00PM - Event wrap up

text: bitenitetucson to 76278

HOTEL OPTION

If you need a room for the evening, please click [here](#) for a discounted group rate of \$183. Self parking is \$20 a night and valet is \$25.

Tucson Marriott University Park

520-792-4100
880 E 2nd St, Tucson, AZ 85719

PARKING

Please plan to park in the Cherry Ave Parking garage located on the corner of Cherry Ave and Enke Dr.

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Didn't get all your questions answered? No problem!
Give us a call at 602-297-3800
or email Angie at angie@alsaz.org

[Click Here for Tucson Bite Night Tickets!](#)

[Click Here for Phoenix
Bite Night Tickets!](#)

• NEW DATE! APRIL 25 - 27, 2025 •



FREE
REGISTER NOW!



JOE'S CAMP

A CAMP FOR KIDS WHOSE FAMILY HAS BEEN TOUCHED BY ALS
Organized by The Joe Martin ALS Foundation

**APRIL
25-27**

Ages 8-13

**Camp Cherokee,
Kings Mountain
State Park, SC**



Delivered by  **the
joe
martin**
ALS FOUNDATION

Partnering with:  **ALS
United**
North Carolina

Register for Free Today!

Out-of-State Campers: Travel sponsorships are available; please contact the Joe Martin Foundation to learn more:

help@joemartinalsfoundation.org

or

www.joemartinalsfoundation.org/joescamp/



In Remembrance

We extend our deepest sympathy and continued support to the families and friends of:

Livia Aguillon, Terri Dillard, Deborah Donegan, Diane Fletcher, Joseph Harris, Roseann Hernandez, Balvina Jensen, Mary Maynes, Gilbert McCaslin, Lynda Rando, Cecile Raths, Douglas Steinmetz, Richard Stepp

[Give Online Here](#)

[Unsubscribe](#)

[ALS Arizona](#)

360 E Coronado Ste 140 Phoenix, AZ 85004