

Sign up for
ALS Link:



<https://bit.ly/3CqGbhb>

Thank you for joining the webinar!

We are admitting audience members from the waiting room
Please allow a few moments for the webinar to begin



HEALEY ALS Platform Trial

Community Q&A – January 22, 2026



Calico



Healey & AMG Center

Sean M. Healey & AMG Center for ALS
at Massachusetts General Hospital



THE ARTHUR M. BLANK
FAMILY FOUNDATION



The AMG Foundation

Navigating Clinical Research Opportunities

- **ClinicalTrials.gov** – clinicaltrials.gov/
- **NEALS** – neals.org/als-trials/neals-affiliated
- **ALS TDI Trial Navigator** – www.als.net/als-trial-navigator/
- **MGH** – www.massgeneral.org/neurology/als/research/als-clinical-trials
- **ALS Signal (I AM ALS)** – www.iamals.org/get-help/als-signal-clinical-research-dashboard/
- **MDA** – www.mda.org/research/clinical-trials
- **ALSA** – www.als.org/research/finding-als-research-opportunities
- **International Alliance of ALS/MND Associations** – www.als-mnd.org/support-for-pals-cals/research/understanding-als-mnd-research/



NEALS Clinical Trial Liaison

Phone: (855) 437- 4823

Email: alstrials@neals.org



ALS & Participation in Clinical Research

LES
TURNER
ALS
FOUNDATION



ALS & PARTICIPATION IN CLINICAL RESEARCH

A Les Turner ALS Foundation Guide for People Living with ALS

Scan to view guide in English

<https://bit.ly/3ZmhZon>



ELA Y PARTICIPACIÓN EN INVESTIGACIONES CLÍNICAS

Una guía hecha por la Les Turner ALS Foundation para personas viviendo con ELA

Escanea para ver la guía en español

<https://bit.ly/3ZnE31R>

“Your ALS Guide”

Information about participating in various types of research

- ALS Clinical Trials
- Expanded Access
- Off Labels and Alternative Therapies
 - ALS Untangled: www.alsuntangled.com/
- Observational Studies
- Tissue Donation



www.youralsguide.com/research-and-clinical-trials.html

VA ALS Website

Veterans Health Administration

- Where to go for care at VA (interactive maps)
- VA resources for ALS
- Educational videos for veterans with ALS and caregivers
- Research information



<https://www.va.gov/health/als.asp>



Added Considerations for Participating in Research

What to expect in the enrollment process

- You don't always have to be a patient at the center where a study is being offered, but it's helpful to connect with a doctor who knows about ALS research
- Finding an ALS specialist or research center near you
 - NEALS member site finder: neals.org/about/neals-member-sites
 - ALS Geospatial Hub Clinic Locator: als-geospatial-hub-nonprofit.hub.arcgis.com/pages/als-clinic-advisor

Note about international participation

- There are important logistics to consider if looking to participate in a US-based trial while living internationally
 - International Alliance of ALS/MND Associations: www.als-mnd.org/support-for-pals-cals/research/understanding-als-mnd-research/
 - Clinical Trials in the European Union: euclinicaltrials.eu
 - Clinical Trials throughout Europe: www.tricals.org/centres

Multi-Center Clinical Research Opportunities

Investigational Medication Trials

- ☐ [HEALEY ALS Platform Trial Phase 2-3s](#)
NCT 04297683
- ☐ [Healey ALS MyMatch Trial Program Phase 1-2s](#)
- ☐ [Study of COYA 302 for the Treatment of ALS \(ALSTARS\) Phase 2](#)
NCT 07161999
- ☐ [Usnoflast Neuromuscular Investigation for Treatment Efficacy in ALS \(UNITE-ALS\) Phase 2b](#)
NCT 07023835

Biomarker & Observational Studies

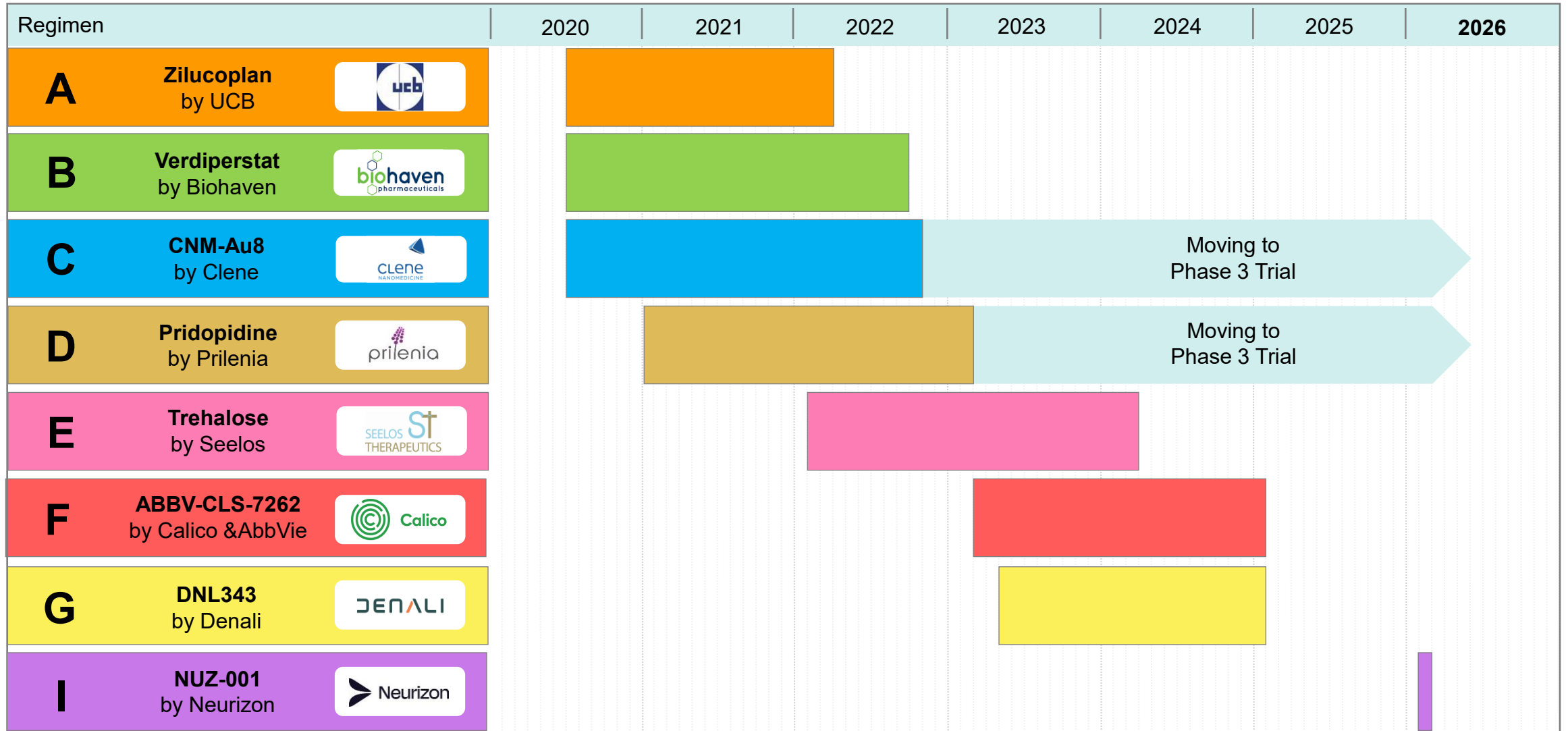
- ☐ [ASSESS ALL ALS](#)
NCT 06578195
- ☐ [PREVENT ALL ALS](#)
NCT 06581861
- ☐ [Target ALS](#)
NCT 05137665

Healey & AMG
Center website:

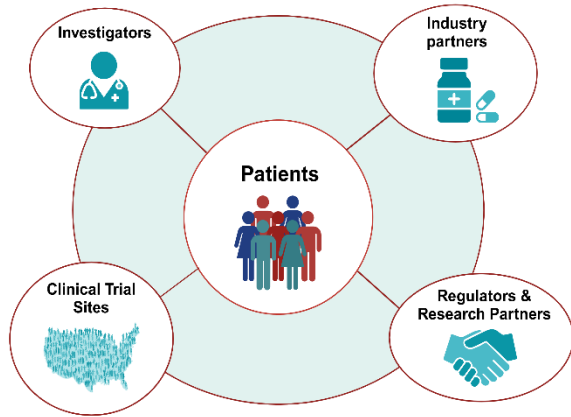


<https://bit.ly/4a4yPhM>

HEALEY ALS Platform Trial



The trial learns from its experience and adapts



Revised the Master Protocol to:

- Increase statistical power
- Streamline operations
- Add even more patient-centered features

Study Duration

9 months RCT followed by ATE

Inclusion Criteria

2 years since symptoms onset

Visit Schedule

Increased remote visits (patient-centered)

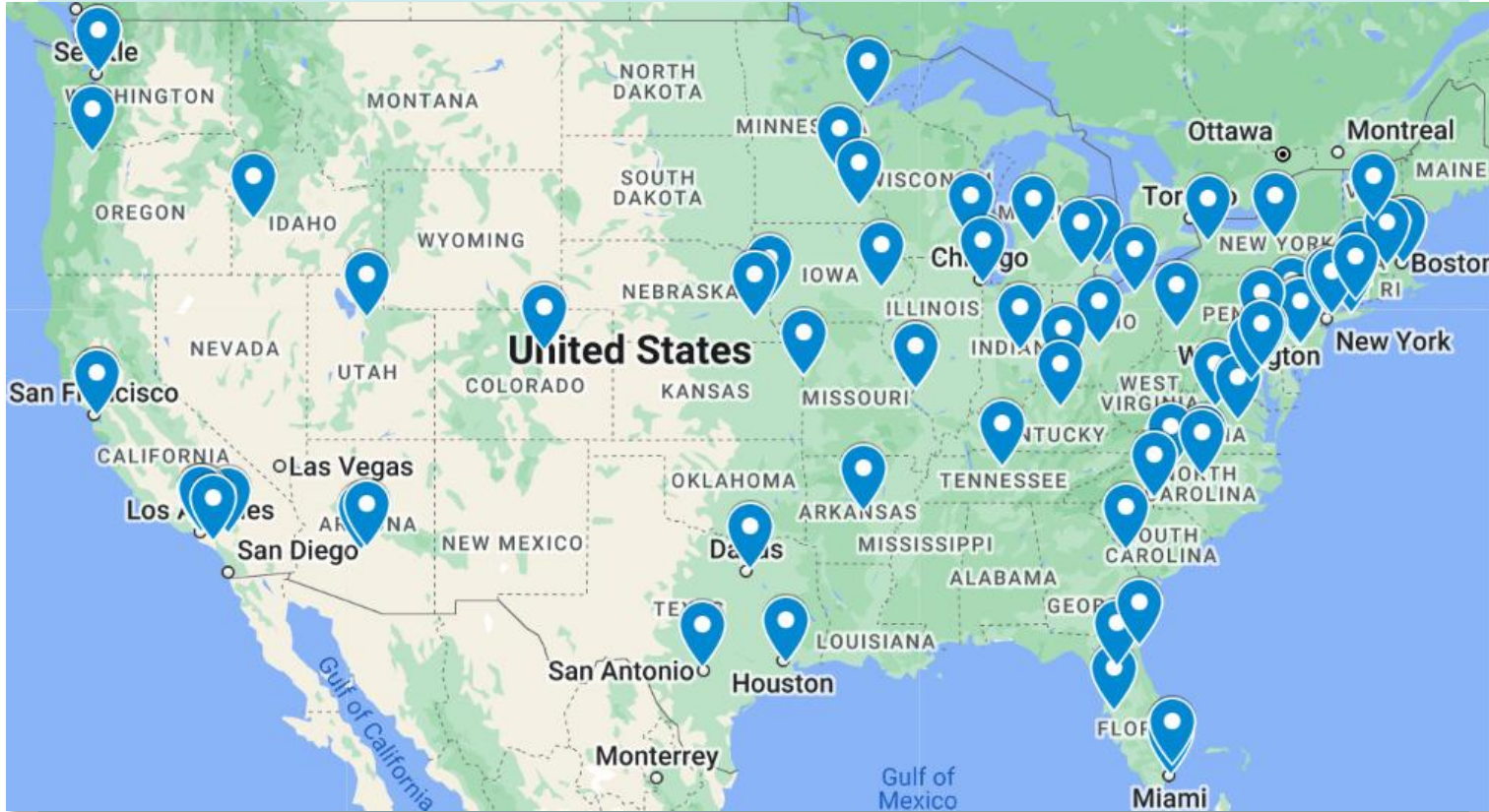
Biomarkers

New biomarkers and PBMCs for stem cells



New regimens will enroll under the revised Master Protocol

Operating across a network of ALS centers of excellence in the US



70+ Sites

Site Map & Contacts:



<https://bit.ly/3g2NZr5>

How to track site enrollment status

Sites marked "Recruiting" are currently enrolling participants. Sites marked "Active, Not recruiting" are active in the Platform Trial (for example, they are following participants in ongoing regimens that have already completed enrollment) but are not enrolling new participants at this time.

Site	State	Enrollment Status	Trial Contact Information
University of Arkansas	AR	Active, Not Recruiting	Shellah Rogers (501-398-8622)
Barrow Neurological Institute	AZ	Active, Not Recruiting	Whitney Dailey
Mayo Clinic Scottsdale	AZ	Active, Not Recruiting	Alissa Bojko (480-301-4902)
Cedars-Sinai Medical Center	CA	Active, Not Recruiting	Viviana Valencia

Site Map & Contacts:



<https://bit.ly/3g2NZr5>

How to check eligibility criteria

A few key criteria are that participants must

- Be at least 18 years old
- Have ALS diagnosis (sporadic or familial)
- Be within 24 months of weakness symptom onset
- Have Vital Capacity score $\geq 50\%$ of predicted value
- Be able to safely swallow pills and liquids

Eligibility Checking Tool



<https://bit.ly/4r4Y8pJ>

ClinicalTrials.gov



<https://bit.ly/3LtH65z>

Tips to make the most of that first touchpoint

When contacting a site, it is helpful to share

- Where you live (town/state if resident of USA)
- Where you currently receive clinical care for ALS
- Month and year of weakness onset due to ALS
- Predicted % value of your most recent Vital Capacity measurement (forced or slow) and date of test
- Whether you are able to safely swallow pills and liquids
- Your contact information and preferred method of communication

Eligibility Checking Tool



<https://bit.ly/4r4Y8pJ>



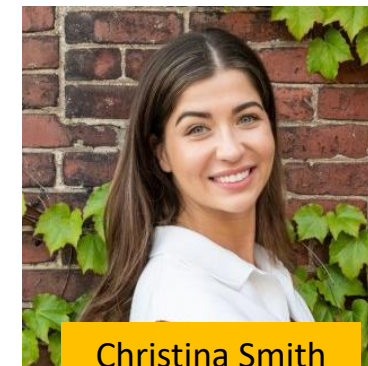
Judi Carey



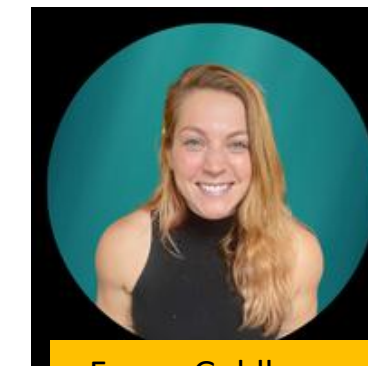
Catherine Small



Michelle Redenz



Christina Smith



Emma Goldberg



Emma Allen

Educational Webinar Opportunities

- **NEALS** – neals.org/people-living-with-als/educational-webinars
- **Les Turner ALS Foundation** – lesturnerals.org/support-services/als-learning-series/
- **Everything ALS** – www.everythingals.org/events
- **ALL ALS** – www.all-als.org/webinars/

Missed a webinar?
View recordings
online!



Stay Connected to News in ALS Research



Catherine Small
Patient Navigator

Patient Navigation – Central resource for people living with ALS

Phone: 833-425-8257 (HALT ALS)

E-mail: healeyalsplatform@mgh.harvard.edu

**Two webinars
each month!**

**Register for
webinars:**



<https://bit.ly/3r6Nd2L>

Upcoming Webinars (Thurs, 5:00- 5:30pm Eastern Time)

February 12 – RAPA-501 EAP Update with Rapa Therapeutics

February 26 – Neurofilament Light Chain (NfL) Analysis in ALS Research

