

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.



ALL ALS Study Updates



Robert Bowser, Barrow Neurological Institute

James Berry, Mass General Hospital

01/23/2025

ALLALS

Access for ALL in ALS



West Coordinating Center

- Located at Barrow Neurological Institute
- Contact PI: Robert Bowser



East Coordinating Center

- Located at Massachusetts General Hospital
- Contact PI: James Berry

35 Clinical Sites



WEST

- Barrow Neurological Institute
- Columbia University
- Washington University
- Georgetown University
- University of Washington
- University of California, San Diego
- Northwestern University
- Mayo Clinic
- Massachusetts General Hospital
- University of Colorado Denver
- Ohio State University
- Universidad de Puerto Rico
- Saint Alphonsus Regional Medical Ctr
- Henry Ford Health
- University of Michigan
- University of Minnesota
- University of California, Irvine
- Providence Brain and Spine
- University of Utah

EAST

- Texas Neurology
- Virginia Commonwealth University
- Temple University
- Pennsylvania State Medical Center
- Duke University
- Dartmouth Hitchcock
- University of Nebraska
- Our Lady of the Lake Regional Medical Ctr
- Indiana University ALS Center
- Emory University
- Hospital for Special Care
- University of California, San Francisco
- University of Alabama, Birmingham
- Johns Hopkins University
- Houston Methodist
- NIA/NINDS Clinical Research



ALL ALS is leading the charge in ALS research with two groundbreaking studies

The **ALL ALS PREVENT** study focuses on understanding the earliest stages of the disease in people at risk,

while the **ASSESS ALL ALS** study collects vital data on individuals living with ALS to track disease progression and identify new biomarkers



Site Activations



- 28/35 Sites have sIRB Approval
- 18/35 Sites Activated
- Sites activated within 7 weeks of sIRB Approval

**Sites sIRB
Approved**



80%

**Sites
Activated**



51%

Current active sites



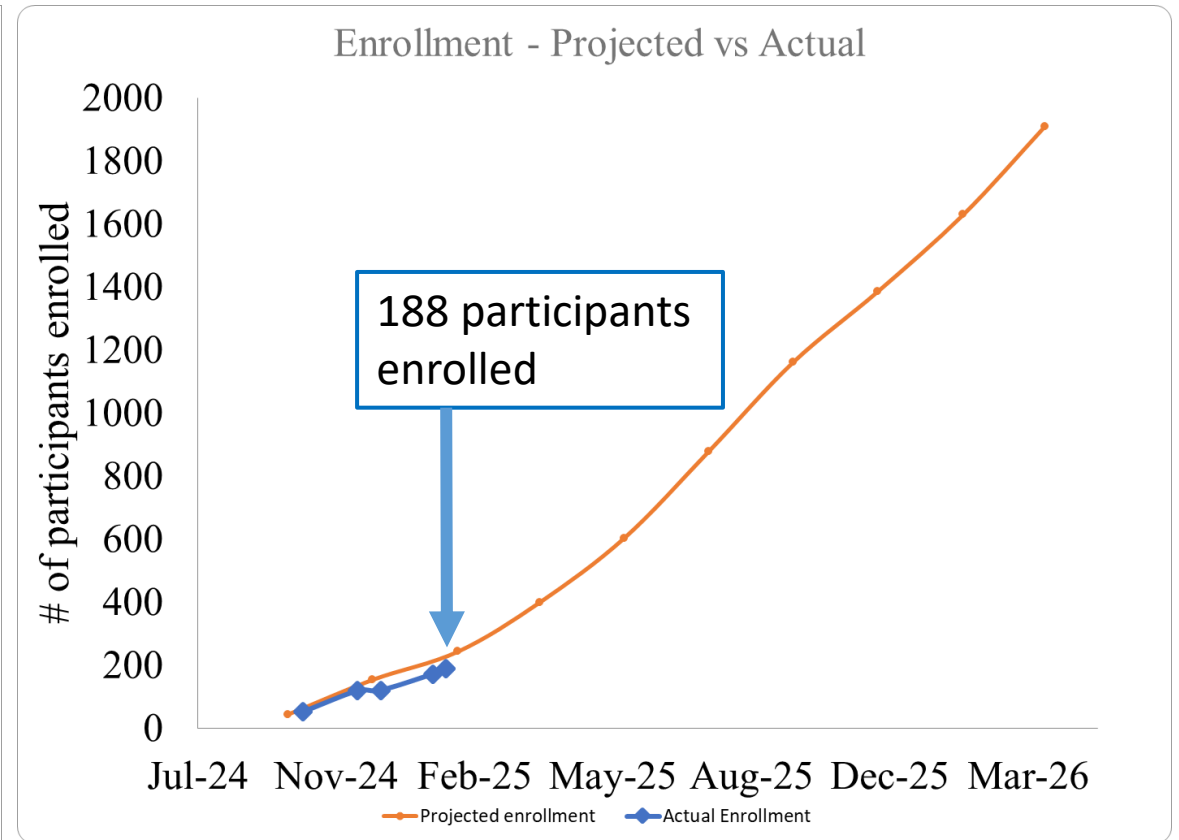
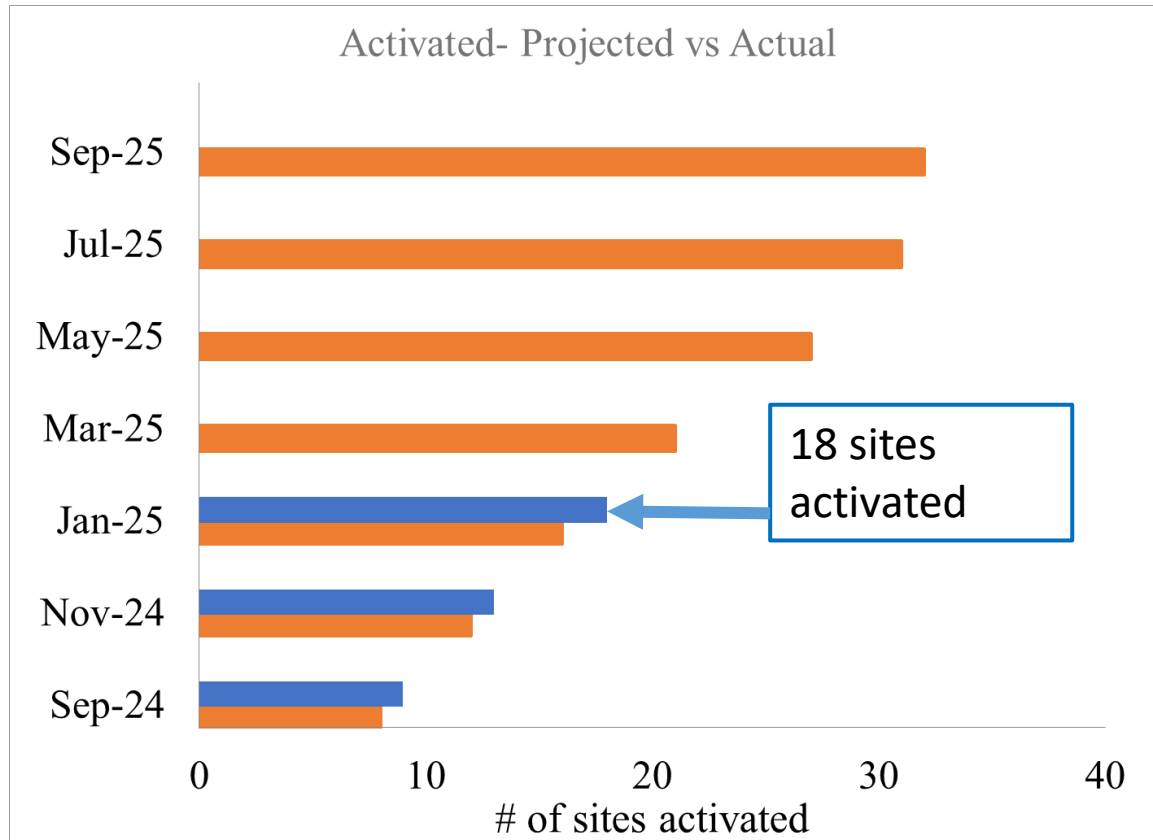
188 participants enrolled as of 01/22/25



| | Symptomatic Onsite | Symptomatic Offsite | Controls |
|--------|--------------------|---------------------|----------|
| ASSESS | 67 | 12 | 28 |

| | Main PREVENT Study | Genetic Testing Results Sub-Study |
|---------|--------------------|-----------------------------------|
| PREVENT | 81 | 10 |

Activation and Enrollment



How to Get Involved: ALL ALS Website

all-als.org



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Access for ALL in ALS

ABOUT ALL ALS STUDIES TEAM PRESS/NEWS PARTICIPATE

Access for ALL in ALS

Funded by the National Institutes of Health (NIH), the Access for ALL in ALS Consortium (ALL ALS), is a community of two coordination centers and 35 research sites across the United States, conducting a combined longitudinal natural history study and biomarker collection study for ALS.

ALL ALS research engages with people currently living with ALS, potential ALS gene carriers, and family members, friends, and community partners to better understand all stages of ALS disease progression.

About Us

ALL ALS STUDIES BY THE NUMBERS

| | | | |
|---|-------------------------------------|---|---|
| 18 Total Number of Active Sites | 183 Participants Enrolled | 4,918 Number of Blood Sample vials* | 679 Number of CSF Sample vials* |
|---|-------------------------------------|---|---|

Track Study Progress

Where Can I Participate?

Study visits will be conducted during routine clinical visits or as stand-alone research visits, with either a combination of in-person and remote visits or entirely remote visits. Please see the map and site list below to find the study site closest to you!



Find an ALL ALS Site

ALL ALS Consortium Participant Interest Intake Form

If you wish for a member of study team to contact you about the ALL ALS consortium, please include your name and preferred contact information below:

Contact Information

- 1) First Name
- 2) Last Name
- 3) City of Residence
- 4) State of Residence
- 5) Zipcode
- 6) Phone number Include Area Code
- 7) E-mail
- 8) Are you interested in participating in ALL ALS Consortium Studies?
- 9) Questions/Comments for Study Staff

Expand

Complete a PIF

How to Connect with ALL ALS

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- ALL ALS Website: all-als.org



- **ClinicalTrials.gov**
 - ASSESS ALL ALS ([NCT06578195](https://clinicaltrials.gov/ct2/show/study/NCT06578195))
 - PREVENT ALL ALS ([NCT06581861](https://clinicaltrials.gov/ct2/show/study/NCT06581861))
- **NEALS Trial Finder** <https://tools.neals.org/als-clinical-trials/>
- **Email Directly**
 - Info@all-als.org



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Access for ALL in ALS



West Coordinating Center

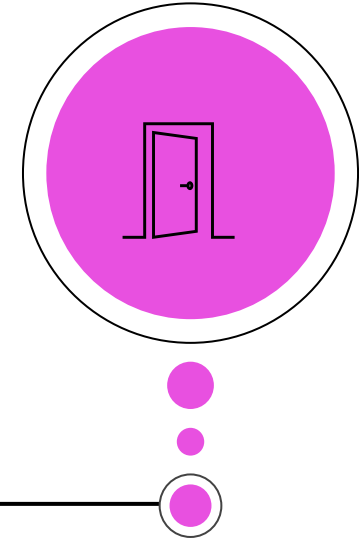
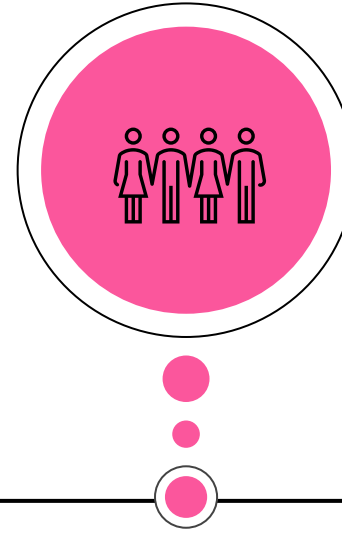
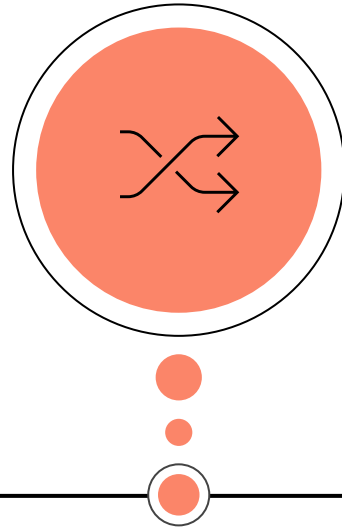
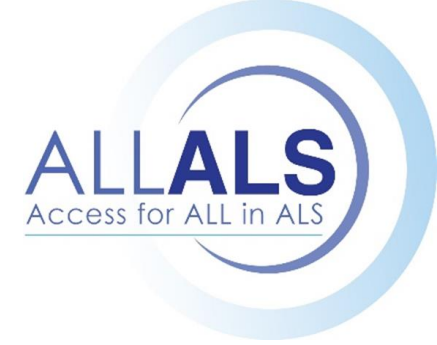
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What are the Goals of ALL ALS?



Accelerate Research Outcomes

Collecting large amounts of data to share with researchers around the world!

Integration

Combining data from past and current studies to fill in gaps in natural history knowledge

Community

Feel connected through community webinars, newsletters, and social media

Accessibility

Participate at one of the 35 clinical sites, or completely remotely!