

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



West Coordinating Center

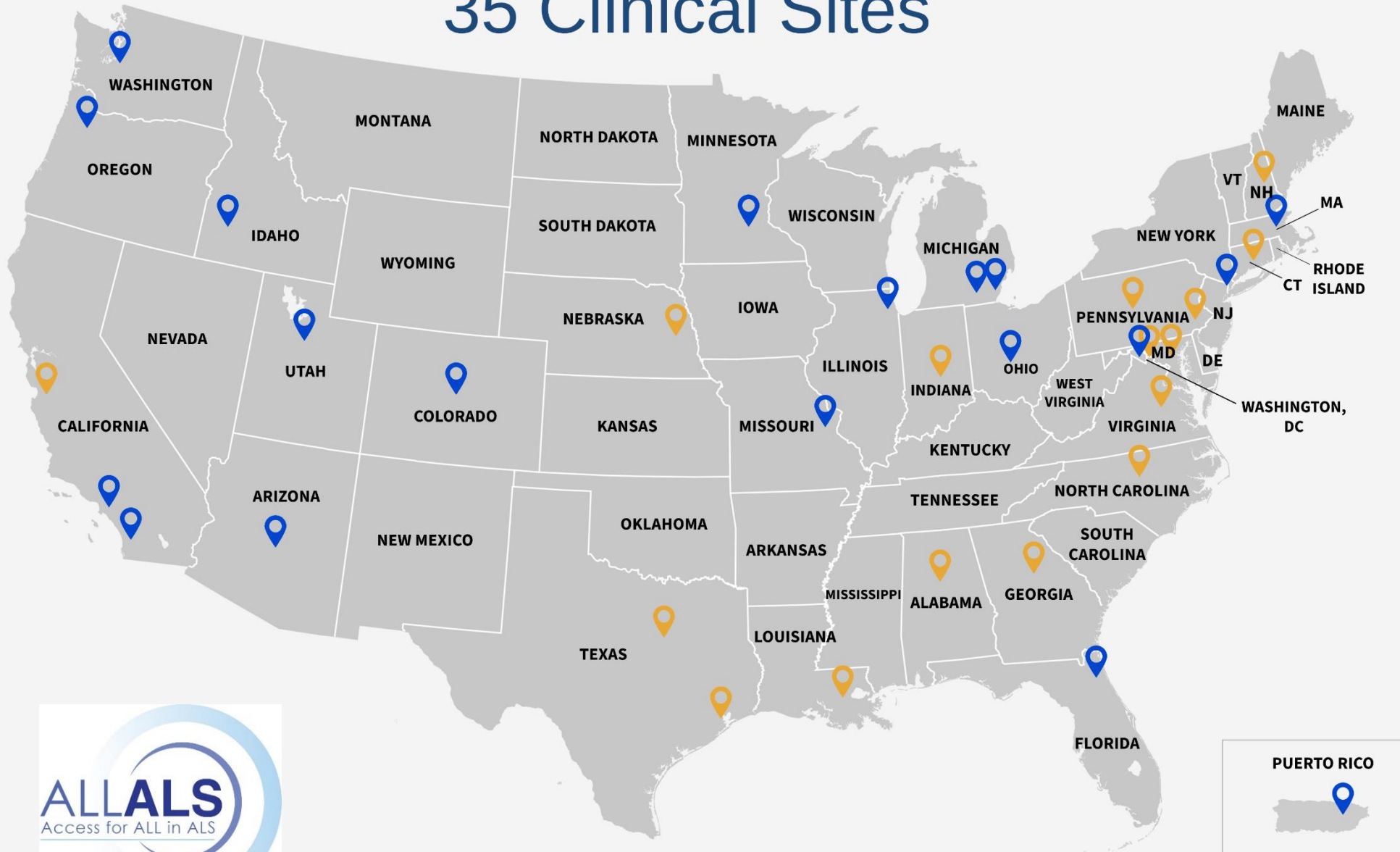
- Located at Barrow Neurological Institute
- Contact PI: Robert Bowser



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



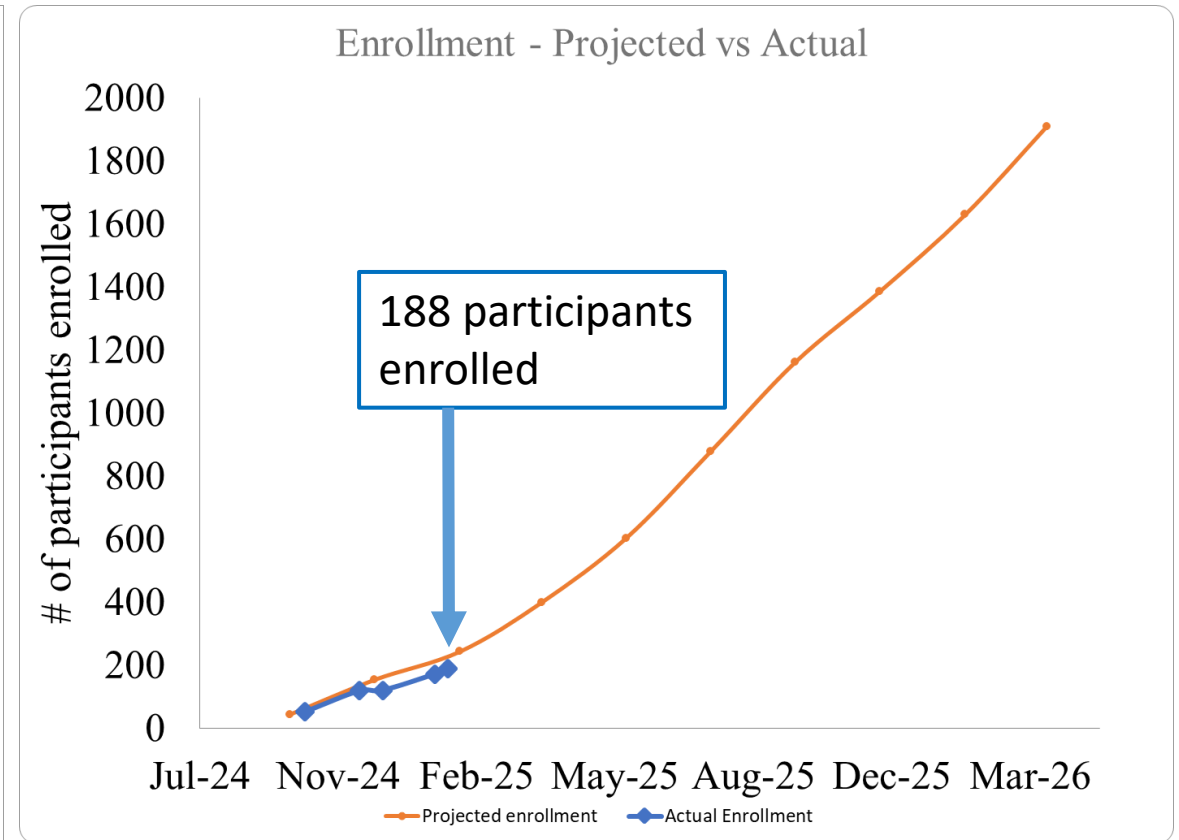
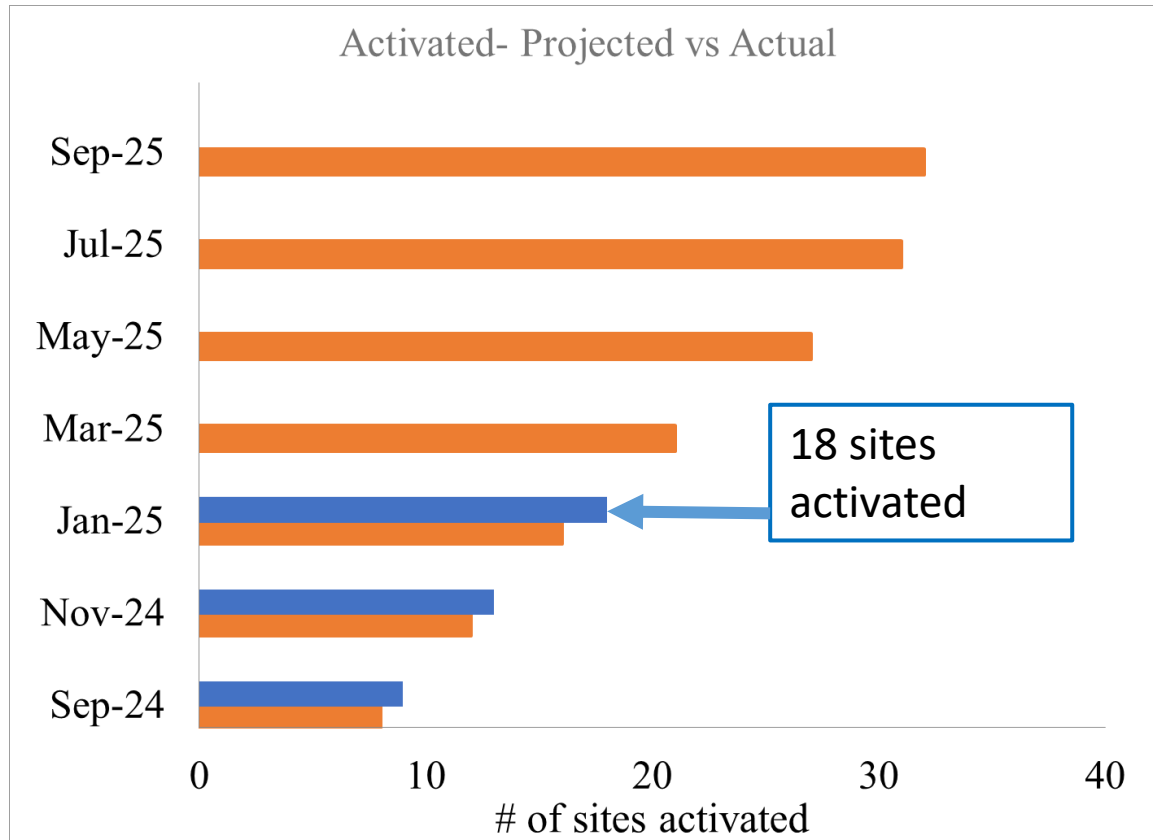
188 participants enrolled as of 01/22/25



	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



ALL ALS
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*
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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



- 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





West Coordinating Center

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



East Coordinating Center

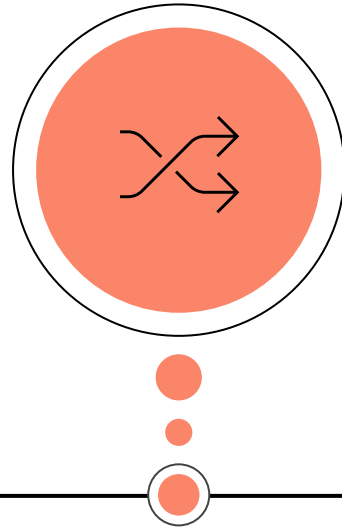
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What are the Goals of ALL ALS?



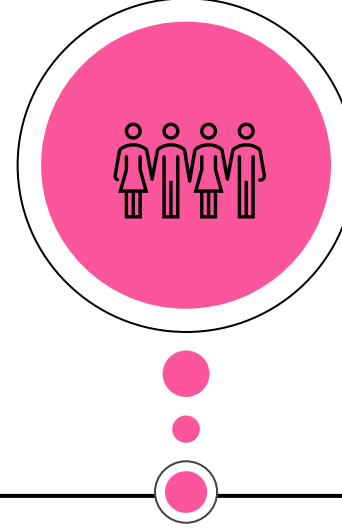
Accelerate Research Outcomes

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



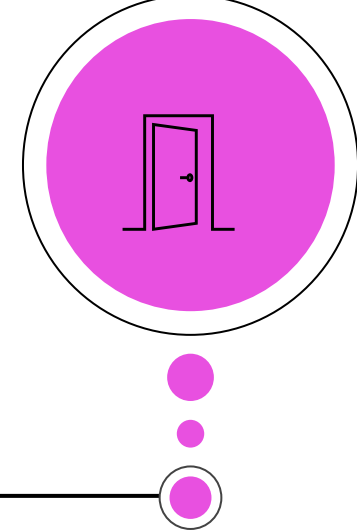
Integration

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!