

Thank you for joining the weekly webinar!

We are admitting audience members from the waiting room.

**Please allow a few moments for the webinar to begin.**



# HEALEY ALS Platform Trial

Weekly Q&A – August 17, 2023



## Healey & AMG Center

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



The AMG Foundation

# Guest Speaker- Gwen Petersen



# ALS Office Hours FAQs:



**Q: I want to be more involved in ALS research. Where do I start?**

**A:** Sign up for Healey Center research updates by emailing: [healeycenterforals@mgh.harvard.edu](mailto:healeycenterforals@mgh.harvard.edu).

Join ALS TDI's ALS Research Collaborative (ARC): <https://arc.als.net/>.

Apply to be a NEALS Research Ambassador: <https://neals.org/>.

You can sign up to receive Research Notifications through The National ALS Registry: <https://www.cdc.gov/als/>.

ALS TDI's Clinical Trials page: <https://www.als.net/als-research/als-clinical-trials/>.

Sign up for global clinical trial updates from ALS TDI: [info@als.net](mailto:info@als.net).



**Q: What vitamins and supplements are you taking? What does your regimen consist of?**

**A:** Here is a link to Dr. Bedlack's most recent ALSUntangled webinar called 'Vitamins and Supplements in ALS':

<https://neals.org/people-living-with-als/educational-webinars/alsuntangled-vitamins-and-supplements-in-als>

Richard Bedlack on ALS Reversals: An Update for 2022 (EverythingALS webinar):

<https://www.youtube.com/watch?v=TKBkx3gJ41Q>

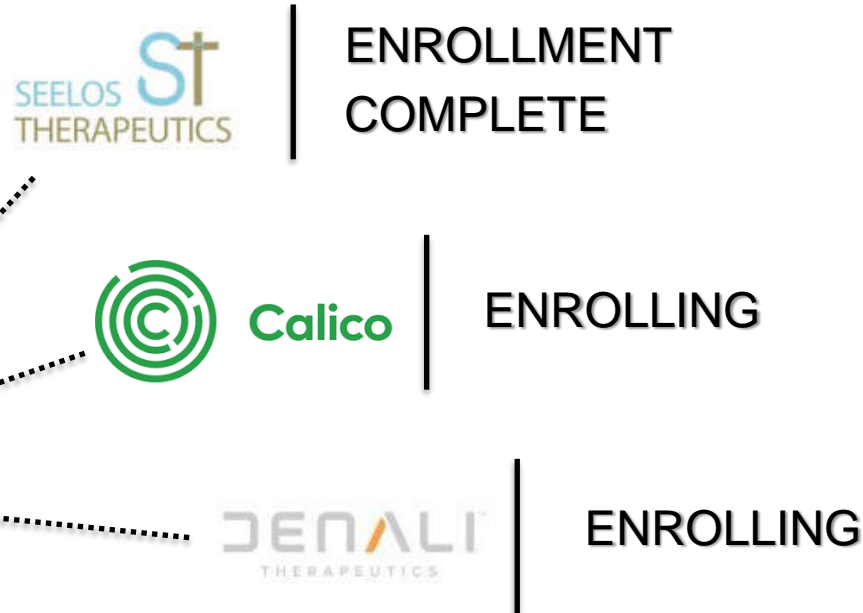
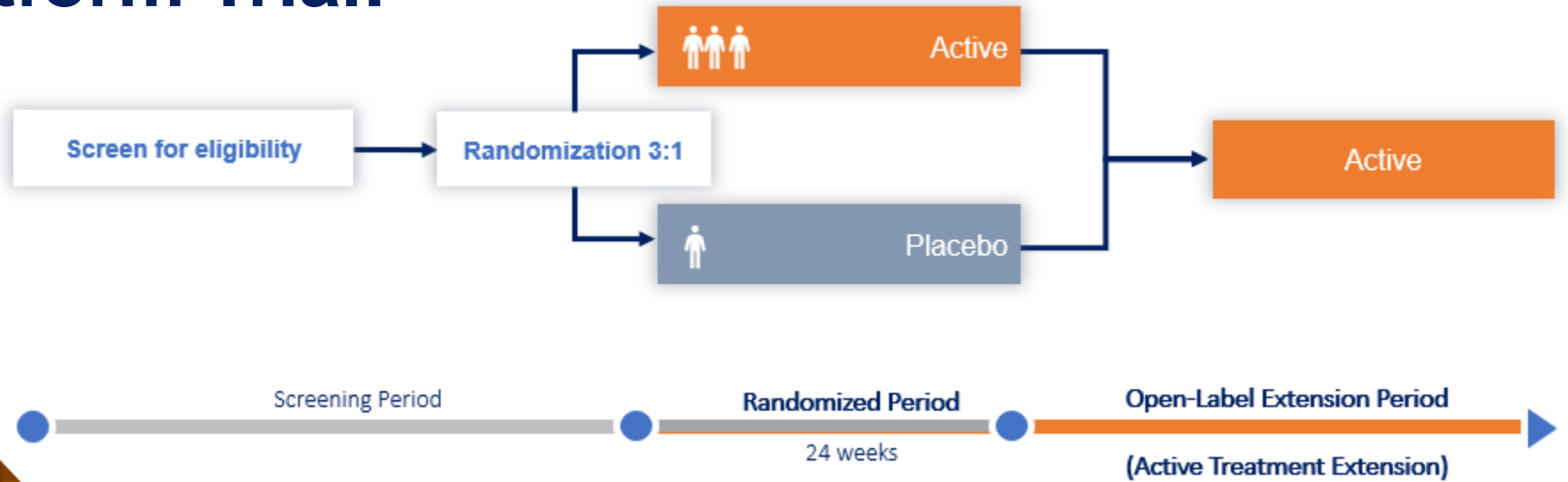
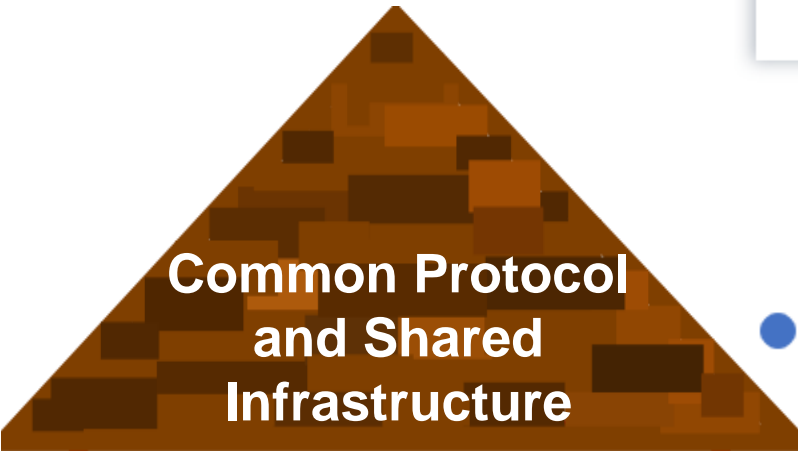


**Q: Do I need genetic testing? How do I get genetic testing?**

**A:** I say yes but talk to your doctor. Prevention Genetics x Ionis: <https://bit.ly/3OTB3pK>. They will mail a kit to home, so there is no need to go anywhere. A doctor needs to approve the request, but it does not need to be a neurologist – it can be a PCP as well. If you enroll in ARC, ALS TDI will sequence your genome at no cost. You can meet with a genetic counselor, either in-person or via telehealth, through the National Society of Genetic Counselors (NSGC): <https://www.nsgc.org/>.



# HEALEY ALS Platform Trial:



# Enrollment Update: Regimen F and Regimen G

269

Participants consented to Master Protocol since RGF and RGG initiated



216

Participants assigned to RGF or RGG



162

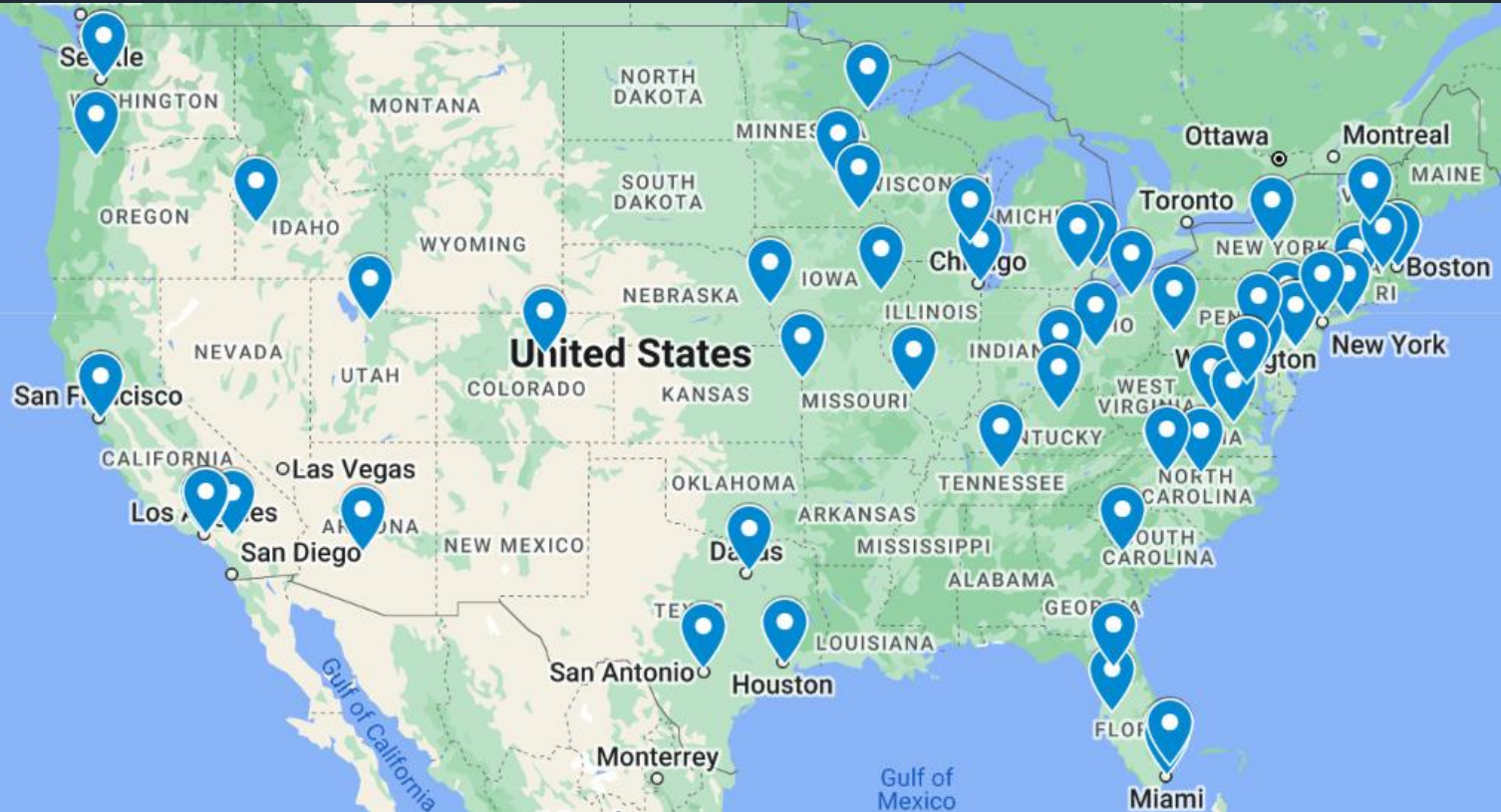
Participants randomized within RGF or RGG  
(enrollment goal ≈240 per regimen, ≈480 total)

*Thank You*

for your partnership in ALS research

(as of 8/17/23)

# 59 Sites Currently Active



(as of 8/17/23)

- ✓ Nova Southeastern University
- ✓ Essentia Health
- ✓ Texas Neurology
- ✓ Mass General Hospital
- ✓ University of Nebraska
- ✓ Hospital for Special Care
- ✓ Henry Ford Hospital
- ✓ Augusta University
- ✓ Beth Israel Deaconess
- ✓ University of Texas HSC
- ✓ University of Colorado
- ✓ Loma Linda University
- ✓ Ohio State University
- ✓ Cedars Sinai Medical Center
- ✓ Duke University
- ✓ Wake Forest University
- ✓ Saint Alphonsus
- ✓ UMass Worcester
- ✓ Lehigh Valley
- ✓ Thomas Jefferson
- ✓ University of South Florida
- ✓ University of Pennsylvania
- ✓ SUNY Upstate
- ✓ University of Iowa
- ✓ California Pacific Med Center
- ✓ Houston Methodist
- ✓ Vanderbilt University
- ✓ University of Minnesota
- ✓ Washington University
- ✓ Barrow Neurological Institute
- ✓ University of Miami
- ✓ Temple University
- ✓ University of Virginia
- ✓ Johns Hopkins University
- ✓ University of Southern CA
- ✓ Holy Cross Hospital
- ✓ University of Washington
- ✓ University of Utah
- ✓ Penn State Hershey
- ✓ University of Michigan
- ✓ University of Kansas
- ✓ Stony Brook University
- ✓ University of Cincinnati
- ✓ Mayo Clinic Rochester
- ✓ Northwestern University
- ✓ Georgetown University
- ✓ Kaiser, Los Angeles
- ✓ University of Pittsburgh
- ✓ Virginia Commonwealth
- ✓ Med College Wisconsin
- ✓ University of CA, San Fran
- ✓ University of Florida, Gainesville
- ✓ Providence Brain and Spine
- ✓ Cleveland Clinic
- ✓ George Washington University
- ✓ Hackensack University
- ✓ Swedish Medical Center
- ✓ University of Kentucky
- ✓ Dartmouth Hitchcock

## Site Map & Contacts:



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

# Checking Site Status Online

Contact a study team near you to discuss enrollment opportunities

## List of Participating Sites

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
Barrow Neurological Institute	AZ	Recruiting	<a href="#">Whitney Dailey</a>
Cedars-Sinai Medical Center	CA	Recruiting	<a href="#">Sophia Mostowy</a>
Forbes Norris MDA/ALS Research Center, California Pacific Medical Center	CA	Recruiting	<a href="#">Teji Dulai</a>
Kaiser Permanente, Los Angeles Medical Center	CA	Recruiting	<a href="#">Mary H. Berganza</a>

Map of Participating Sites



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



# Patient Navigation

## Central resource for people living with ALS



Catherine Small

Phone: 833-425-8257 (HALT ALS)

E-mail: [healeyalsplatform@mgh.harvard.edu](mailto:healeyalsplatform@mgh.harvard.edu)

Weekly webinar  
registration:



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

ALS Link sign-up:



<https://bit.ly/3o2Ds3m>

### Upcoming Webinars:

August 24th- weekly Q&A webinar

*\*August 31st webinar canceled*



Allison Bulat