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 10, 2023** 







### **Healey & AMG Center**

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



















































# Guest Speaker - Steve Witt



Pictured: Steve Witt with wife Dani Faibes Witt and their dog Neptune. Steve and Dani are also pictured with their children, Rebecca and Ben.

# no leg to stand on

I have ALS, and if you're unfamiliar with this incurable, deadly disease, count yourself lucky. Yet there's much I've found unnervingly funny. So join me on this journey, and as I lose neurons and everyday functioning, let's see how long I can keep my sense of humor.

Want to read my journal every month? Subscribe here!





www.nolegtostandon.com

# **Guest Speakers**



Senda Ajroud-Driss, MD

Platform Trial Site Investigator

Northwestern University (Chicago, IL)



Shafeeq Ladha, MD
Platform Trial Site Investigator
Barrow Neurological Institute (Phoenix, AZ)

Understanding HEALEY ALS Platform Trial Study Procedures

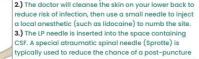
#### LUMBAR PUNCTURE

A Lumbar Puncture (LP), or Spinal Tap, is a procedure to remove a small sample (10-15mL or ~1 tablespoon) of cerebrospinal fluid (CSF) from the lower spine. CSF is the fluid that surrounds the brain and spinal cord, and it contains proteins, cells, and other substances that may be important biomarkers in ALS research. During the procedure, a needle is inserted between two lumbar vertebrae (backbones) in the lower back and into the space in the spinal canal that contains CSF.

Sometimes, people feel worried that a lumbar puncture could be risky or painful. In reality, this is a safe and common procedure to

Get a good night's rest, eat as usual, and stay well-hydrated prior to the LP visit. LUMBAR PUNCTURE 1.) You will be asked to sit or lie down in a position that helps widen the spaces between the bones of the





lower spine.

headache. The doctor may need to readjust the needle if CSF cannot be drawn with the first insertion. 4.) Spinal fluid is collected into specimen tubes for lab testing. The LP needle is removed, your back is cleaned,

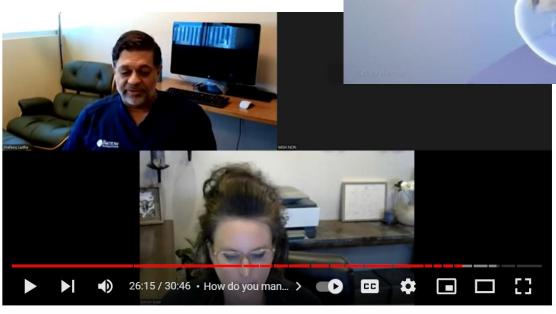
and a band-aid is placed over the LP site. 5.) For your comfort and safety, it is recommended that someone drive you to and from the LP study visit.

**QUESTIONS?** Prior to enrolling in a clinical trial, your study team will discuss the LP procedure with you. Please ask your study team for clarification if you have any questions while reviewing the informed consent form.

### Educational LP Resources

#### **Short Video LP Demo:**





#### Dr. Ladha's Q&A Webinar:



From an accredited US hospital

Learn how experts define health sources in a journal of the National Academy of Medicine [2]

HEALEY ALS Platform Trial Weekly Q&A Webinar: June 22, 2023 | Massachusetts General Hospital

### Study Drugs Webpage

### This public webpage provides:

- 1. Overview of science behind Regimen F and Regimen G
- 2. Links to download relevant brochures, including the Lumbar Puncture Brochure
- 3. Links to view relevant videos and webinar recordings

#### Regimen F: ABBV-CLS-7262, by Calico and AbbVie- Now Recruiting

Watch a webinar about the science behind ABBV-CLS-7262

<u>Watch this video</u> for more information on the mechanism of action behind ABBV-CLS-7262.

Download Regimen F Brochure

Download Lumbar Puncture Brochure

Step by Step Guide to Lumbar Punctures: Watch short video

#### Regimen G: DNL343, by Denali Therapeutics

Download Regimen G Brochure

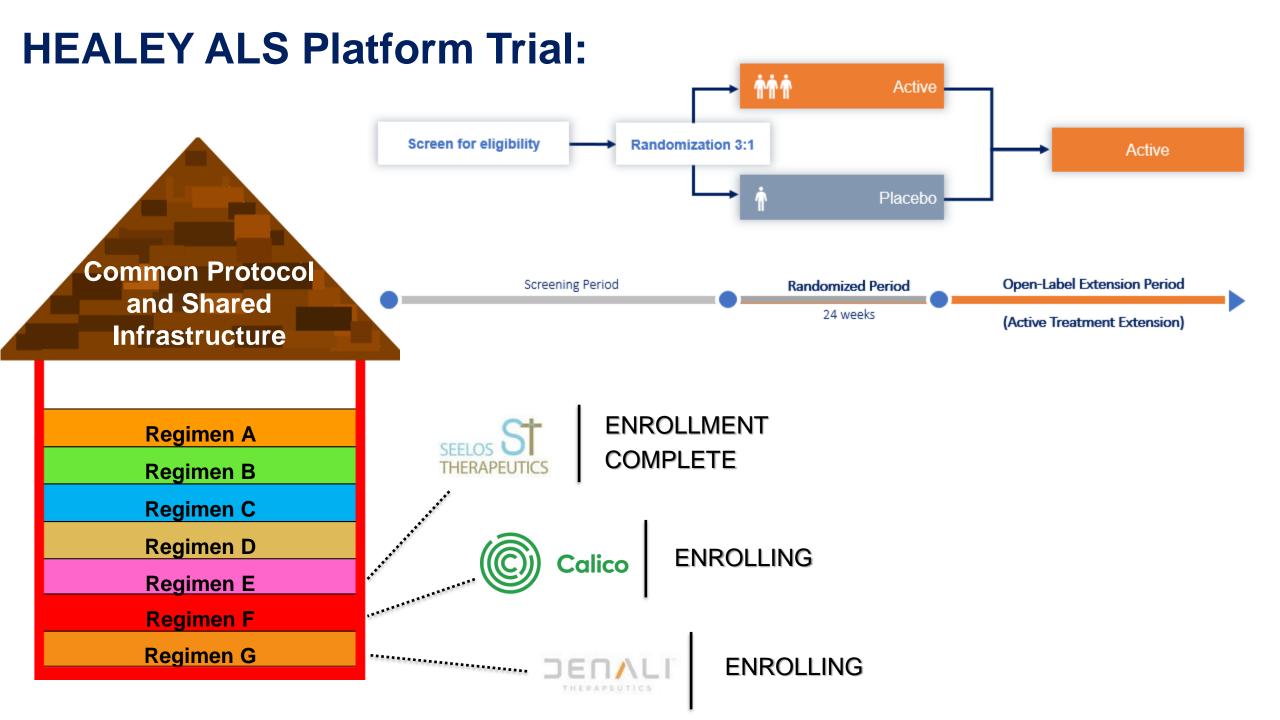
Watch a webinar about the science behind DNL343



https://www.massgeneral.org/neurology/als/research/first-platform-trial-treatments



### **Healey & AMG Center**



## **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	Whitney Dailey
Cedars-Sinai Medical Center	CA	Recruiting	Sophia Mostowy
Forbes Norris MDA/ALS Research Center, California Pacific Medical Center	CA	Recruiting	<u>Teji Dulai</u>
Kaiser Permanente, Los Angeles Medical Center	CA	Recruiting	Mary H. Berganza

Map of Participating Sites





https://bit.ly/3g2NZr5

# Patient Navigation Central resource for people living with ALS



**Catherine Small** 



**Allison Bulat** 

Phone: 833-425-8257 (HALT ALS)

E-mail:healeyalsplatform@mgh.harvard.edu

Weekly webinar registration:



https://bit.ly/3r6Nd2L

**ALS Link sign-up:** 



https://bit.ly/3o2Ds3m

### **Upcoming Webinars:**

August 17th- with guest speaker Gwen Petersen August 24th- weekly Q&A webinar

\*August 31st webinar canceled