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.
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)
**LUMBAR PUNCTURE**

A lumbar puncture (LP), also known as a spinal tap, is a procedure to remove a small sample 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 (vertebrae) 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 collect CSF.

1. **Tips to Prep:** Get a good night's rest and eat a healthy meal before the procedure.
2. **Step by Step:**
   - You will be asked to sit or lie down in a position that helps widen the space between the bones of the lower spine.
   - The doctor will cleanse the skin on your lower back to reduce risk of infection, then use a small needle to inject a local anesthetic (such as lidocaine) to numb the site.
   - The LP needle is inserted into the space containing CSF. A special type of needle (Eppendorf) is typically used to reduce the risk of injury to the spinal fluid. The needle may need to be adjusted if CSF cannot be drawn with the first insertion.
   - CSF fluid is collected into specimen tubes for laboratory testing. The LP needle is removed, your back is cleaned, and a band-aid is placed over the LP site.
   - For your comfort and safety, it is recommended that you remain flat for 24 hours after the procedure.

**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.

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**Short Video LP Demo:**

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**Dr. Ladha’s Q&A Webinar:**

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**Educational LP Resources**

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**HEALEY ALS Platform Trial Weekly Q&A Webinar: June 22, 2023 | Massachusetts General Hospital**
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
- Watch this video 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 ALS Platform Trial:

- Common Protocol and Shared Infrastructure

- Regimen A
- Regimen B
- Regimen C
- Regimen D
- Regimen E
- Regimen F
- Regimen G

- Screen for eligibility
- Randomization 3:1
- Active
- Placebo

- Screening Period
- Randomized Period: 24 weeks
- Open-Label Extension Period (Active Treatment Extension)

- ENROLLMENT COMPLETE
- ENROLLING
Checking Site Status Online

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.

<table>
<thead>
<tr>
<th>Site</th>
<th>State</th>
<th>Enrollment Status</th>
<th>Trial Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barrow Neurological Institute</td>
<td>AZ</td>
<td>Recruiting</td>
<td>Whitney Dailey</td>
</tr>
<tr>
<td>Cedars-Sinai Medical Center</td>
<td>CA</td>
<td>Recruiting</td>
<td>Sophia Mostowy</td>
</tr>
<tr>
<td>Forbes Norris MDA/ALS Research Center, California Pacific Medical Center</td>
<td>CA</td>
<td>Recruiting</td>
<td>Teji Dulai</td>
</tr>
<tr>
<td>Kaiser Permanente, Los Angeles Medical Center</td>
<td>CA</td>
<td>Recruiting</td>
<td>Mary H. Berganza</td>
</tr>
</tbody>
</table>

Contact a study team near you to discuss enrollment opportunities

https://bit.ly/3g2NZr5
Patient Navigation
Central resource for people living with ALS

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