## **HEALEY ALS Platform Trial**

**Weekly Q&A – June 9, 2022** 













BARROW

Neurological Institute\*



#### **Healey Center**

Sean M. Healey & AMG Center for ALS at Mass General







































#### **Guest Speaker**

Honora Dalamagas, RN, MSN, CNS
Research Manager/Clinical Research Coordinator



Natalie Cartwright, MS
Clinical Research Coordinator



Hospital for Special Care, New Britain CT

# Participating in a Clinical Trial at HFSC





Recruitment

Clinic sees ≈ 250 people with ALS every year

Neurologist introduces research

Meet with Coordinator during Clinic Visit, if interested



**Research Visits** 

Followed by one Coordinator

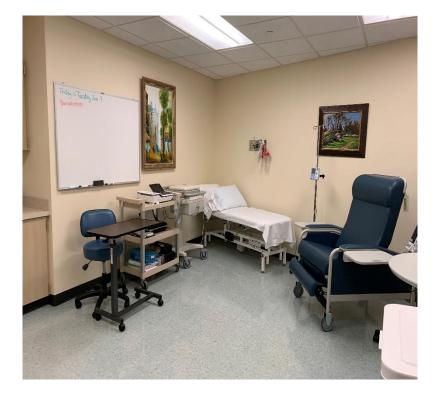
All assessments in one location

**Efficient and Comfortable** 



**Between Visits** 

Communication with Research team
Continuity of care



### Keys to Success as a High Enrolling Site



Top priority = Safety

Excellent Care

→ Retention

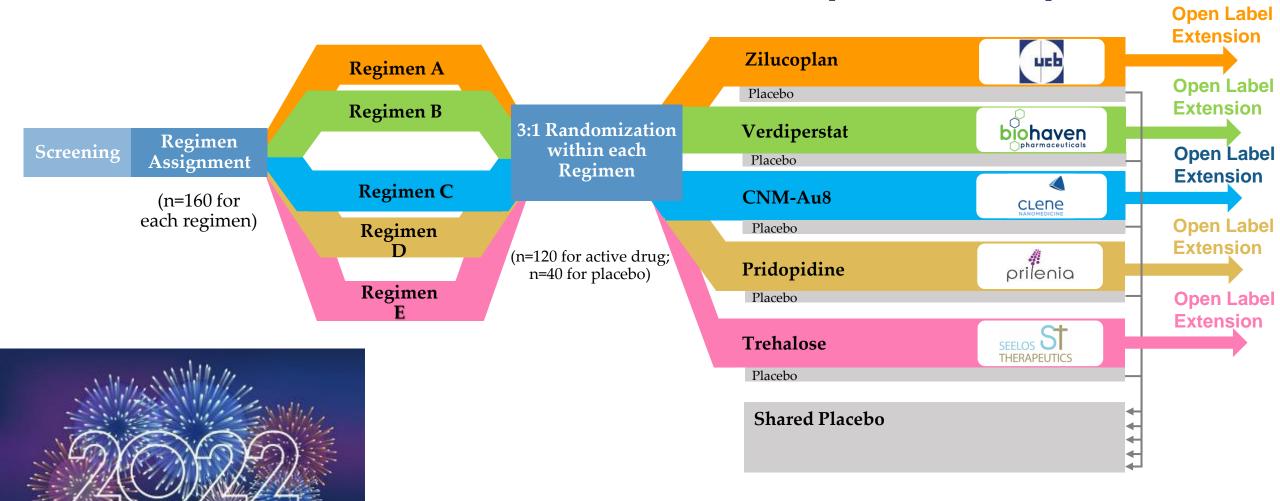
Communication

Documentation

Organization

Consistency

#### The HEALEY ALS Platform Trial is a Perpetual Adaptive Trial



## Enrollment Updates (as of June 9, 2022)

• 71 individuals have signed informed consent

46 individuals have been randomized within Regimen E



This breakthrough trial would not be possible without your participation

Your **partnership** in research is what keeps us filled with passion, dedication, and the commitment to uncover new promising treatments for ALS

**Every research participant, whether on the active drug or placebo, plays a critical role** in making the hope of finding a cure for ALS a reality

### **Checking Site Status Online**

#### List of Participating Sites

Sites marked "Recruiting" are currently enrolling participants in regimen E.

Sites marked "Active, Not recruiting" are active in the platform (for example, they are following participants in regimens A-D) but are not enrolling new participants at this time. Most active sites are expected to start enrolling in regimen E soon.

Site	State	Enrollment Status	Contact Information
Lehigh Valley Health Network	PA	Recruiting	Andrew Orzel (610-402-9543)
Penn State Hershey	PA	Active, Not recruiting	<u>Heidi Runk</u>



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 Guest Speakers:**

June 16th- Bruce Rosenblum (EAP Patient Advisory Committee Member)

June 23<sup>rd</sup>- Jackie Whitesell, MD (Investigator at Saint Alphonsus Medical Center, Idaho)

**June 30**th- Gale Kittle, RN, MPH (Director, Outcomes Measurement Training)



The ALS Association/Northeast ALS Consortium Educational Webinar

## Healey ALS Platform Trial Regimen E: A Participant's Guide

**Friday, June 17, 2022** 5:00 - 6:00 PM EDT

The purpose of this webinar is to provide an overview of how SLS-005 (trehalose) may help to slow ALS and illustrate what potential participants can expect when enrolling in Regimen E of the Healey ALS Platform Trial. The presenters will review some of the unique aspects of the regimen related to the intravenous administration.

#### **Register Below:**



https://bit.ly/3aeT5kc

Recording will later be available under "educational webinars" on neals.org