Guest Speaker

Allison Bulat
Platform Trial Patient Navigator
NEALS Patient Education & Advocacy Committee (PEACe) Co-Chair
NEALS Patient Liaison to the Executive Leadership Team
Sometimes the best views come after the hardest climbs…

NOW

Examples of Research Ambassador Projects

- Ice Bucket Challenge
- Act for ALS
- FDA Guidelines
- Social Security Benefit Delay Removal
- “I’m Dying to Tell You” Podcast Series
- ALS Untangled Podcasts
- Patient Website Reviews
- Research Paper Reviews
- Patient Advisory Boards
- Committee Members for Various Organizations
- Social Media Groups

NEXT CLASS:
November 3rd & 4th - FLORIDA
https://www.neals.org/for-people-with-als-caregivers/clinical-research-learning-institute-crli/
The HEALEY ALS Platform Trial is a Perpetual Adaptive Trial.

Regimen A
- CNM-Au8
- Placebo
- Verdiperstat
- Placebo
- Pridopidine
- Placebo
- Zilucoplan
- Placebo
- Trehalose
- Placebo
- Shared Placebo

Regimen B
- (n=120 for active drug; n=40 for placebo)

Regimen C
- (n=160 for each regimen)

Regimen D

Regimen E

Screening

3:1 Randomization within each Regimen

Open Label Extension
Enrollment Updates (as of July 21, 2022)

- **93** individuals have signed informed consent

- **65** individuals have been randomized within Regimen E

**Thank You**

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.
39 Sites Currently Activated for Regimen E

(as of 7/14/22)

Sites in blue participated in previous regimens. Sites in green (underlined to the side) are new additions to the Platform Trial!

Lehigh Valley Health Network
Mass General Hospital
University of Kansas
University of Maryland
California Pacific Medical Center
Northwestern University
Virginia Commonwealth University
University of Nebraska
Washington University
Wake Forest University
Hospital for Special Care
Saint Alphonsus Regional
University of Massachusetts
Duke University
Barrow Neurological Institute
Georgetown University
Texas Neurology
Beth Israel Deaconess Medical Center
SUNY Upstate
Spectrum Health
Henry Ford Hospital
Essentia Health
University of Southern California
University of South Florida
University of Colorado
Providence Brain and Spine
University of Minnesota
Loma Linda University
University of Iowa
Swedish Medical Center
Ohio State University
University of Cincinnati
Thomas Jefferson University
UC San Francisco
Mayo Rochester
University of Washington
Vanderbilt University
UPMC
Indiana University

Site Map & Contacts:

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:
July 28th - Special Guest – Dr. Lori Chibnik – Biostatistics / Placebos
August 4th – NO WEBINAR WILL BE HELD – Summer Break!
More Special Guests to be Announced!