

HEALEY ALS Platform Trial

Weekly Q&A – July 21, 2022



Healey Center

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



The AMG Foundation

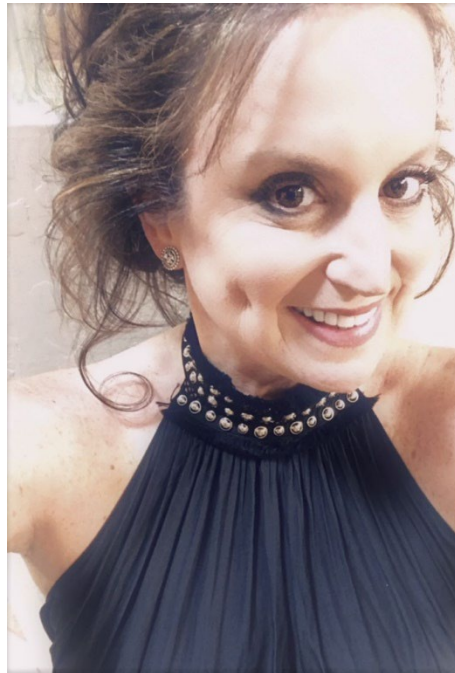
Guest Speaker

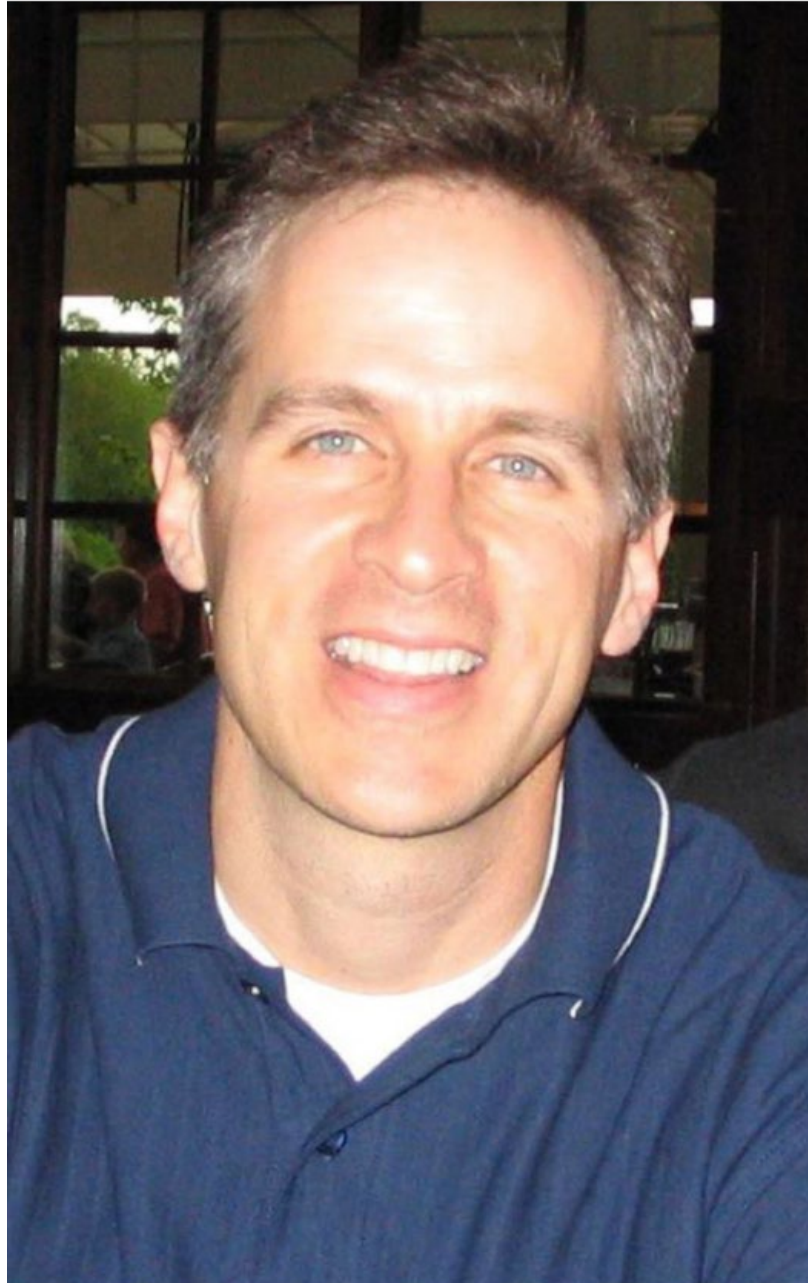
Allison Bulat

Platform Trial Patient Navigator

NEALS Patient Education & Advocacy Committee (PEACe) Co-Chair

NEALS Patient Liaison to the Executive Leadership Team





ALS



PAST



?



FUTURE

Sometimes the best views come after the hardest climbs.....

NOW



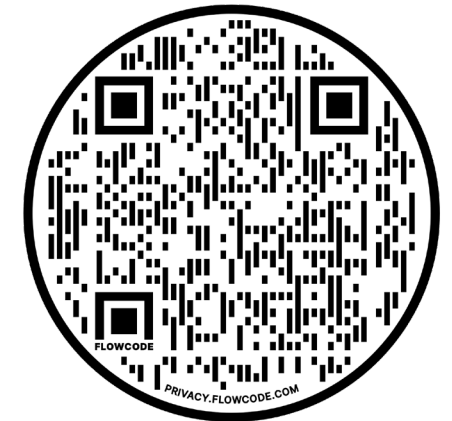
Examples of Research Ambassador Projects

- 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

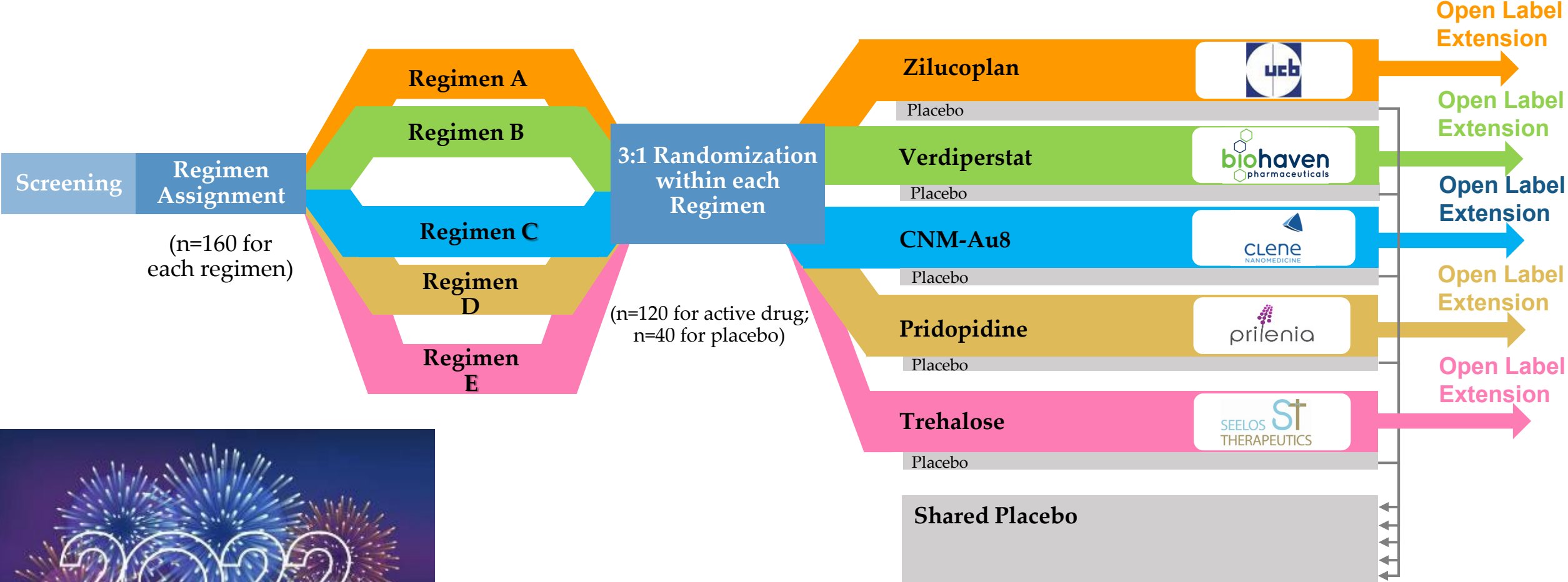
NEXT CLASS:

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



Enrollment Updates (as of July 21, 2022)

- **93** individuals have signed informed consent
- **65** individuals have been randomized within Regimen E

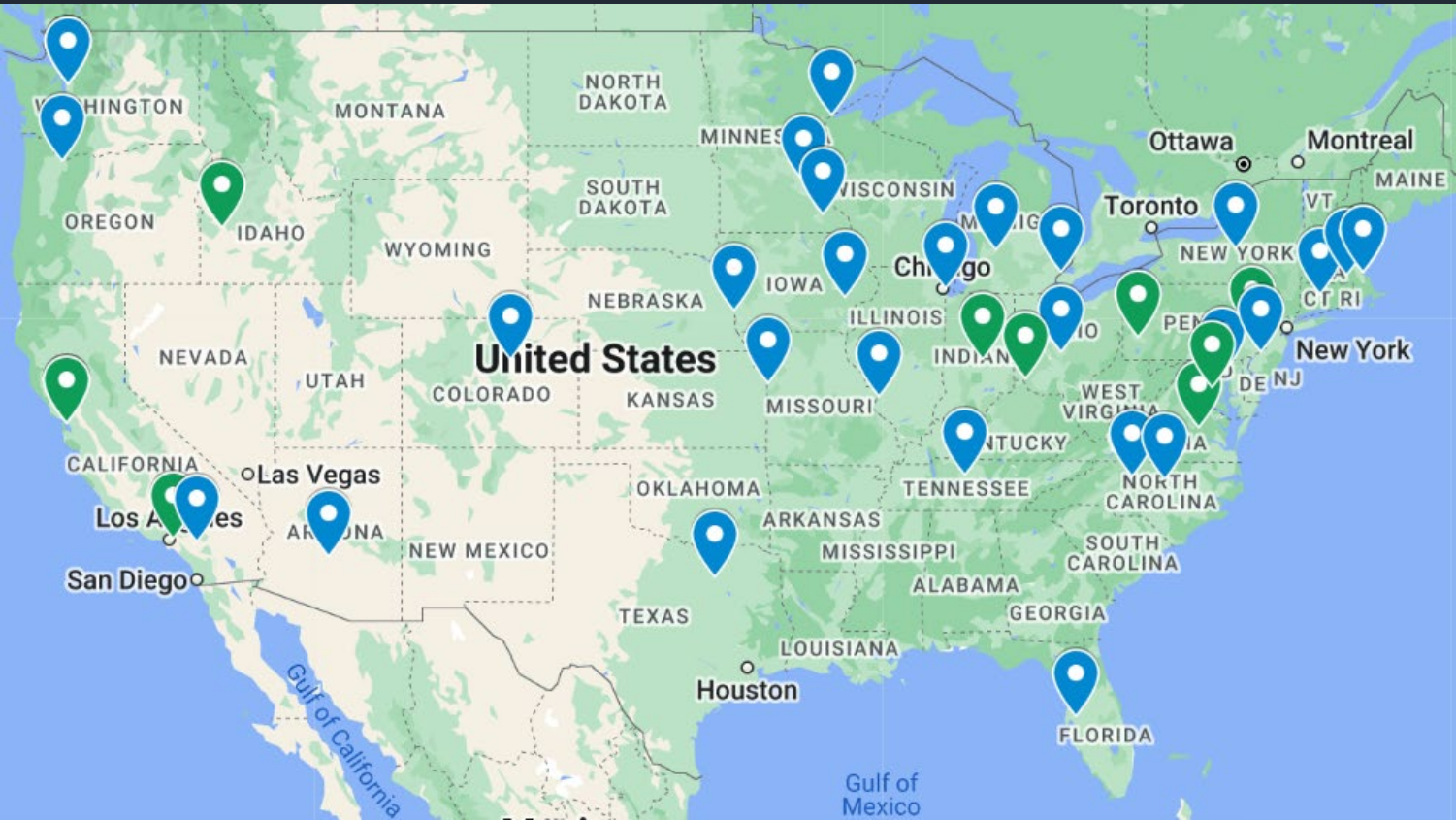
Thank You

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



Catherine Small

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!



Allison Bulat