

HEALEY ALS Platform Trial

Weekly Q&A – June 30, 2022



Guest Speaker

Gale Kittle, RN, MPH

Director, Outcome Measurements Training
Barrow Neurological Institute, Phoenix AZ

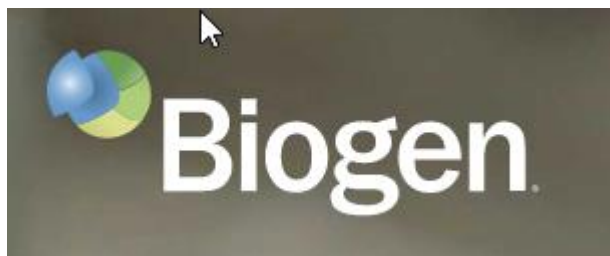


Barrow Neurological Institute Clinical Research Organization

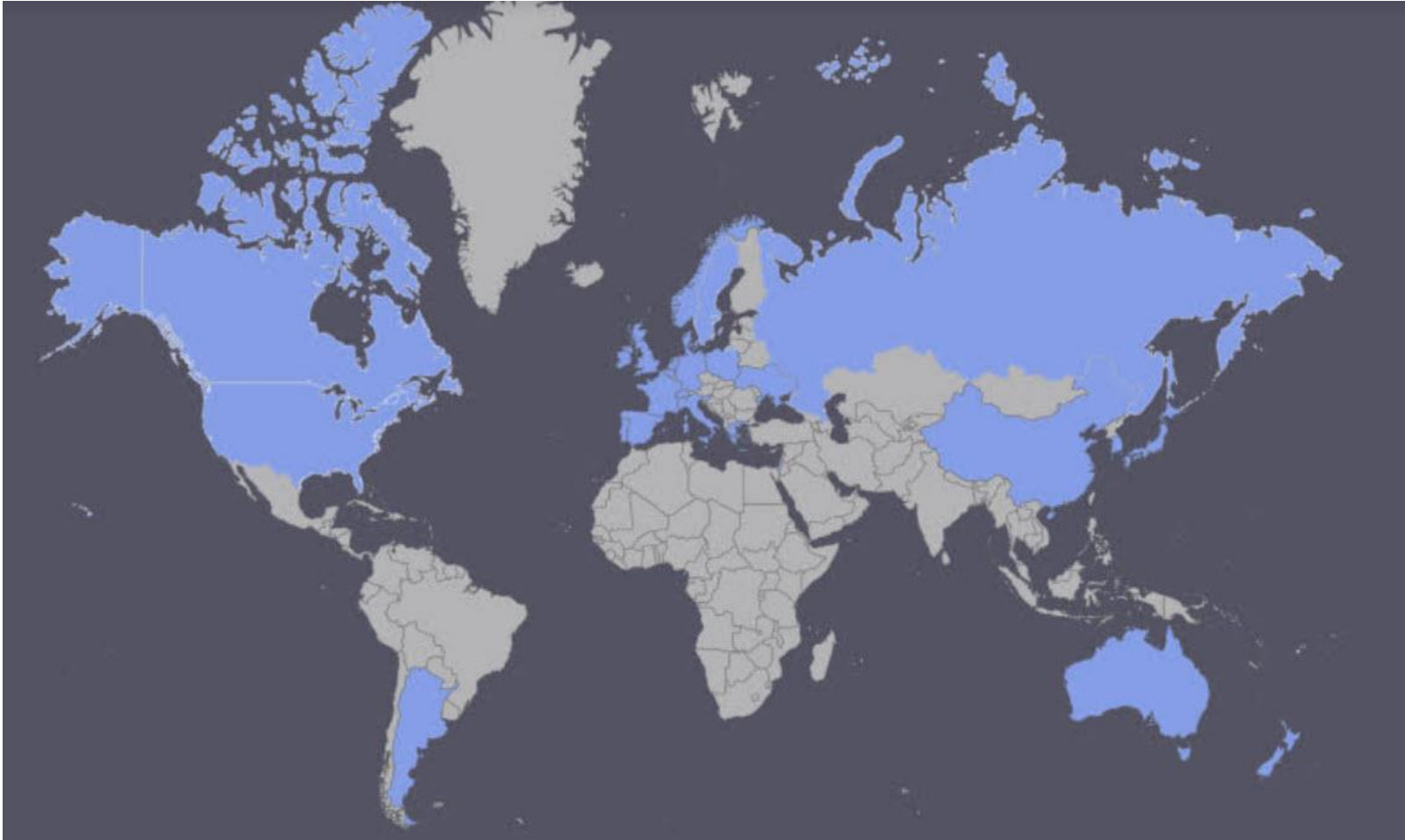
- Outcomes and Clinical Monitoring team specialized in Neurological Disorders.



BNI Outcomes Center: Phoenix, AZ



Trained/certified more than 1,400 evaluators
in 27 countries



Core Outcomes Team



Gale Kittle, RN, MPH
Director/Trainer



Jenny Hamilton,
BA, CCRC
Project Manager



Marlee Lovett,
BS
Research
Assistant



Jasi Torres, BS
Research Assistant

Platform Trial Outcome Measures

ALSFRS-R



Vital Capacity

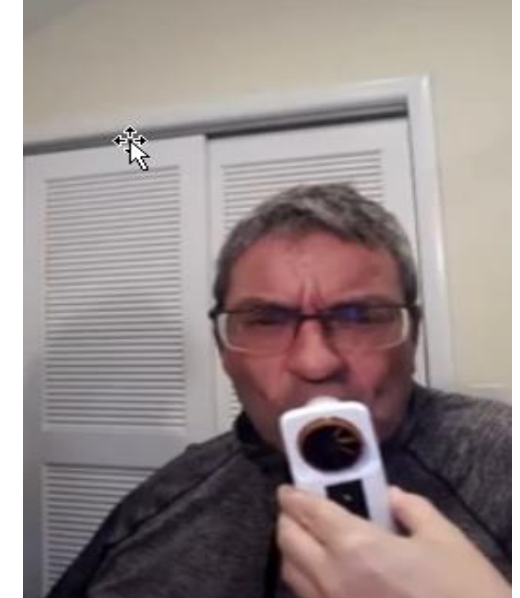


HHD



(Hand-held Dynamometry)

Home Spirometry



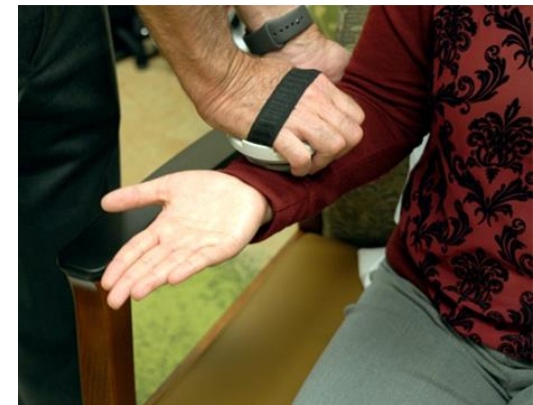
Training and Certification

Training

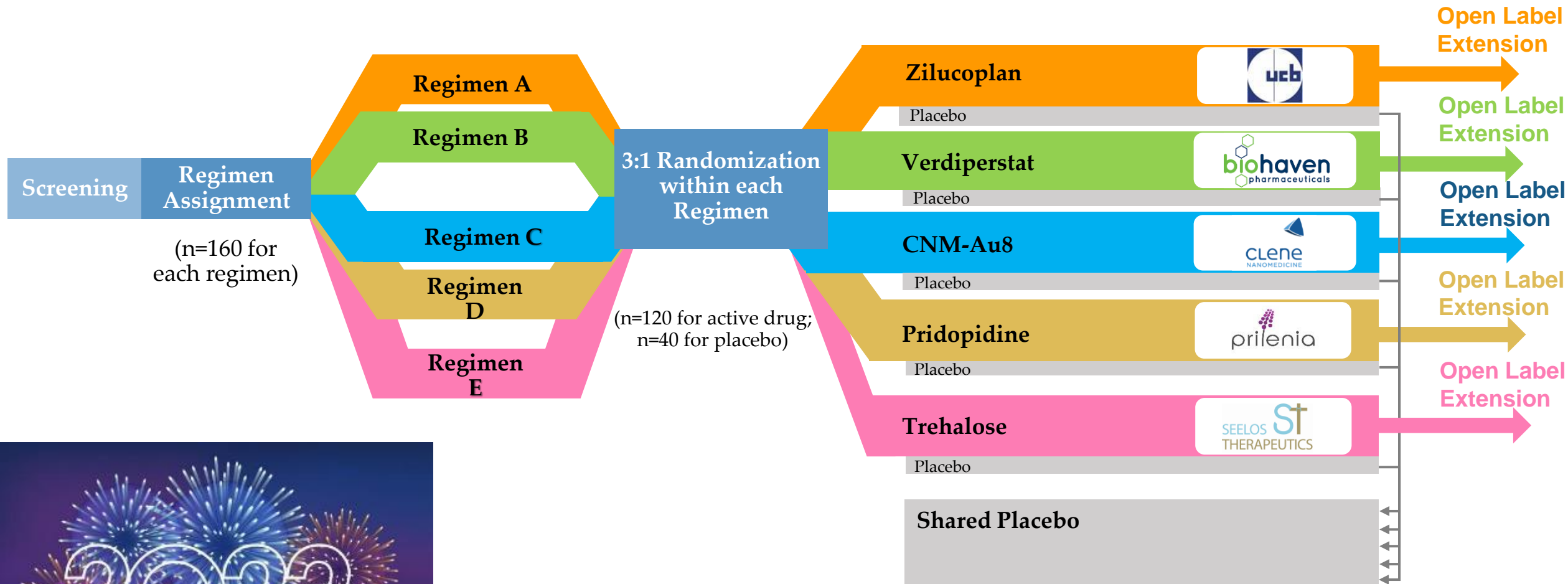
- Investigator Meetings: In-person or virtual
- Self-accessed webinar on training portal
- Real life or video practice/demonstrations

Certification

- Perform practice assessments
- Must meet specific criteria for reliability requirement
- Retests and one-on-one training if required
- Regular certificate renewal (annually or every two years)



The HEALEY ALS Platform Trial is a Perpetual Adaptive Trial



Enrollment Updates (as of June 30, 2022)

- **83** individuals have signed informed consent
- **55** individuals have been randomized within Regimen E

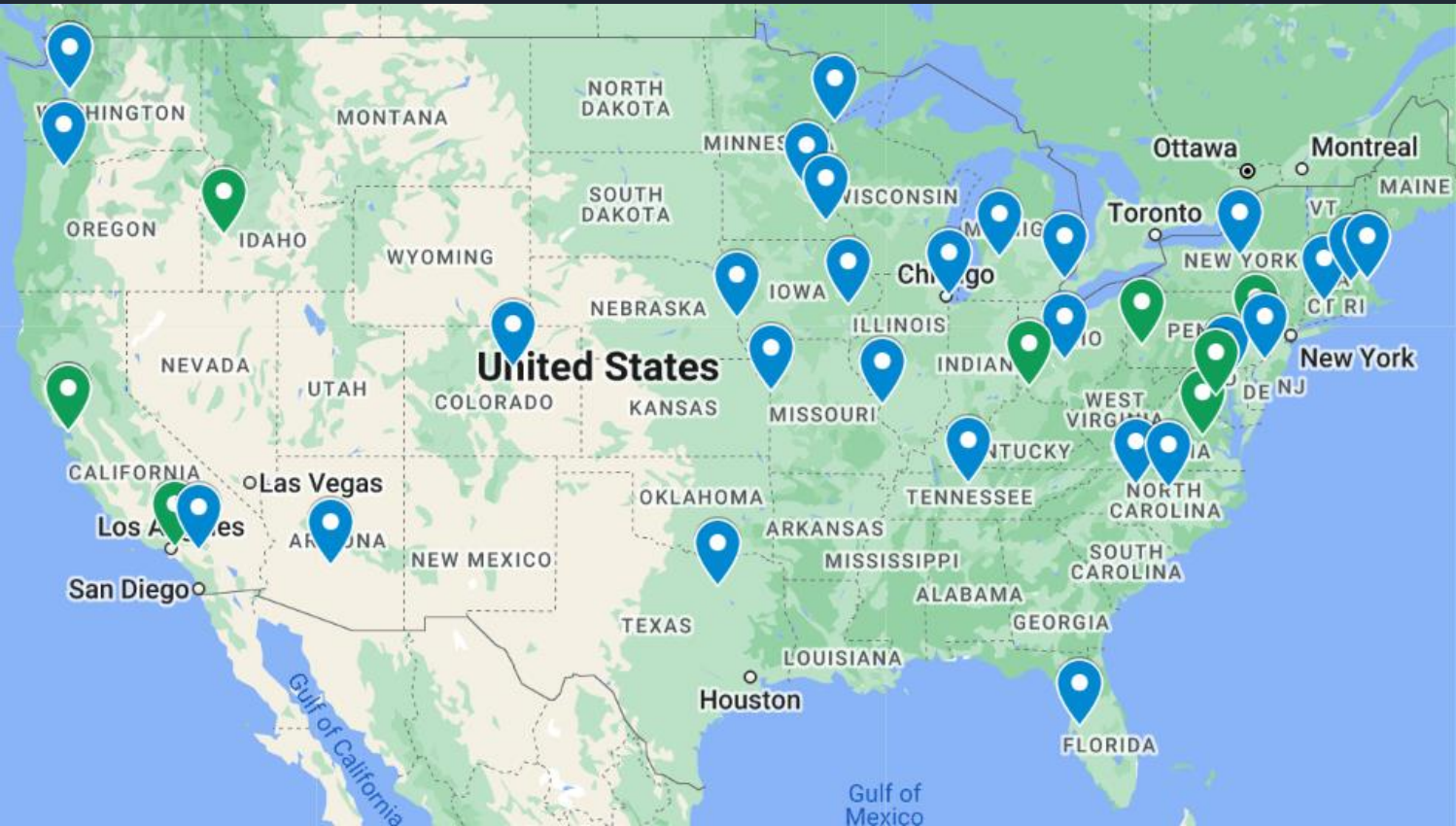
Thank You

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

38 Sites Currently Activated for Regimen E



(as of 6/30/22)

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

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 Guest Speakers:

July 7th- James Berry, MD, MPH (Discussion about Biomarkers)

July 14th- Eufrosina Young, MD (Investigator at SUNY Upstate, New York)



Allison Bulat