HEALEY ALS Platform Trial

Weekly Q&A – July 14, 2022

Guest Speaker

Eufrosina Young, MD
Platform Trial Site Investigator
SUNY Upstate, Syracuse NY

ALS Clinic at SUNY Upstate

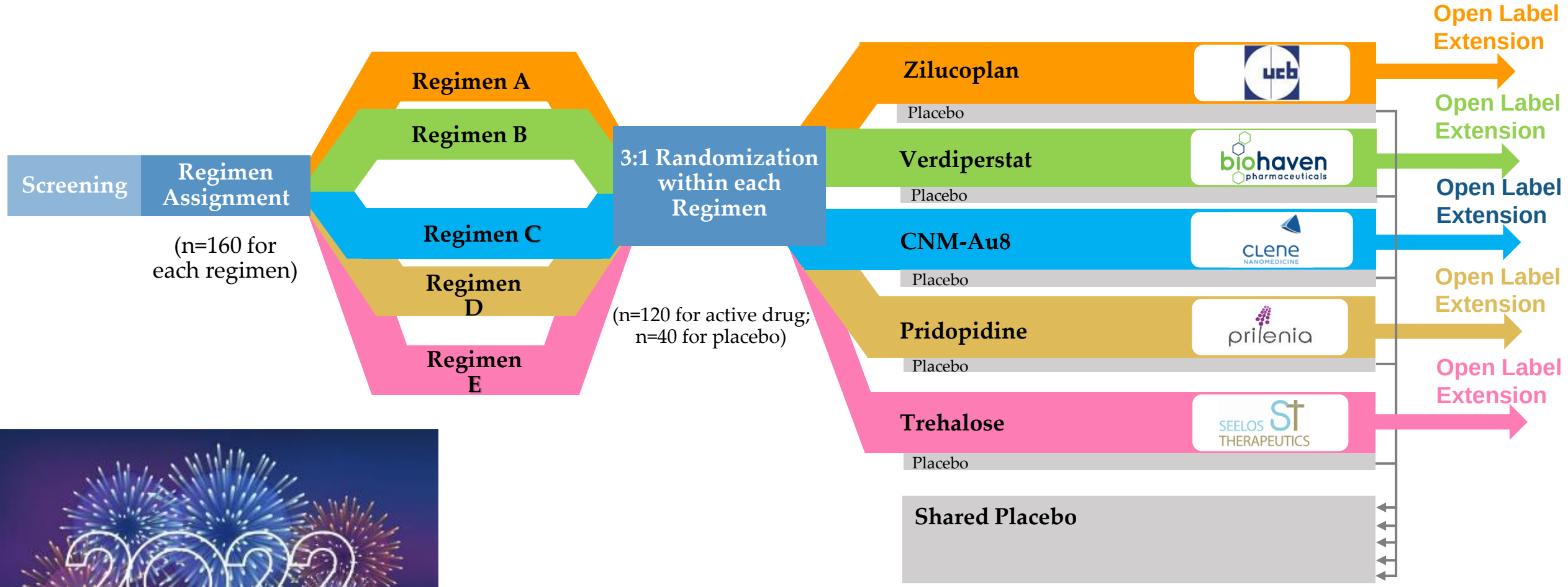
- MD: Dr. Eufrosina Young
- RN's: Jeff Collins, Dawn Dailey
- Clinic Coordinator: Stephanie Lessun, LMSW
- Social Worker: Samantha Ueberroth, LMSW
- Spiritual Care: Father Eric Malcom
- ALSA Care Services Coordinator: Rabecca Coulter, LMSW
- Additional Providers: OT, PT, SLP, RD, RRTs, Research Coordinators

- For clinic coordinator inquiries, please reach out to lessuns@upstate.edu, 315-464-5899.

SUNY Upstate Healey Team

- Site Investigator:
  - Eufrosina Young (YoungEu@upstate.edu)
- Sub-Investigator:
  - Jenny Meyer (MeyerJe@upstate.edu)
- Primary Research Coordinator:
  - Lena Deb (DebL@upstate.edu)
- Secondary Research Coordinator:
  - Marielle DeMasi (DemasiM@upstate.edu)

The HEALEY ALS Platform Trial is a Perpetual Adaptive Trial



Enrollment Updates (as of July 14, 2022)

- **90 individuals have signed informed consent**

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

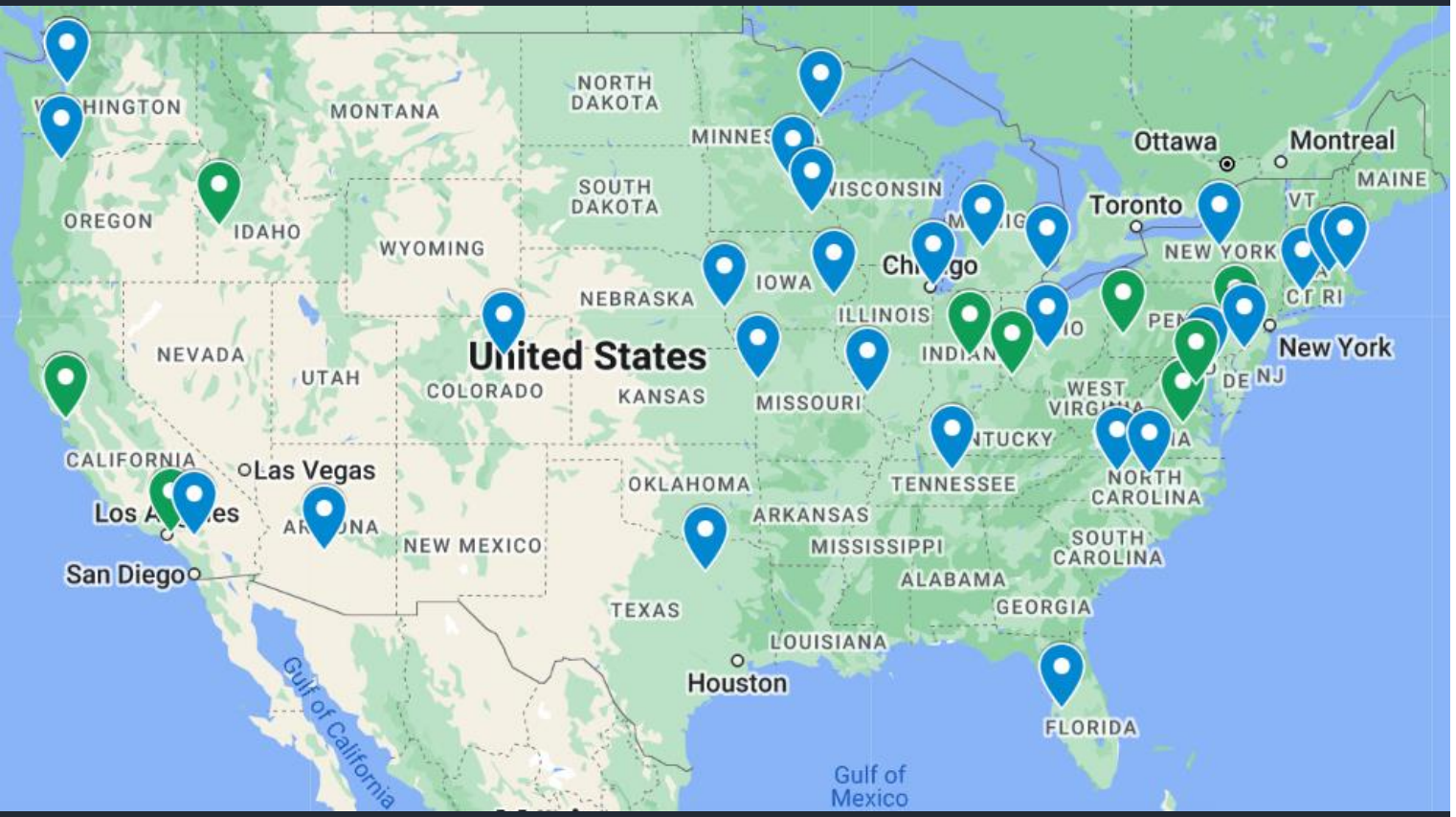
Thank You

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

Trial Updates (as of July 14, 2022)

Indiana University Now Active for Regimen E

Contact: Sandy Guingrich

Email: sguingri@iu.edu (preferred)

Phone: 317-963-7382

Latest News

Read Press Release:

https://bit.ly/3nTKjfg

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:

***TBD* July 28th-** Lori Chibnik, PhD, MPH (Biostatistics Discussion about Placebos)

Genes in ALS

Matthew Harms, MD
Associate Professor of Neurology at Columbia University

Thursday, July 28, 2022
1:00 - 2:00 PM EDT

This webinar will provide an approachable overview of the major genes involved in ALS: what those genes are, how they lead to ALS, and what ideas they are giving scientists for treating all forms of ALS. There will be time at the end of the presentation for questions.

Register Below:

https://bit.ly/3RGpn9l

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