

Thank you for joining the webinar!

We are admitting audience members from the waiting room.

Please allow a few moments for the webinar to begin.



HEALEY ALS Platform Trial

Community Q&A – June 26, 2025



Healey & AMG Center

Sean M. Healey & AMG Center for ALS
at Massachusetts General Hospital



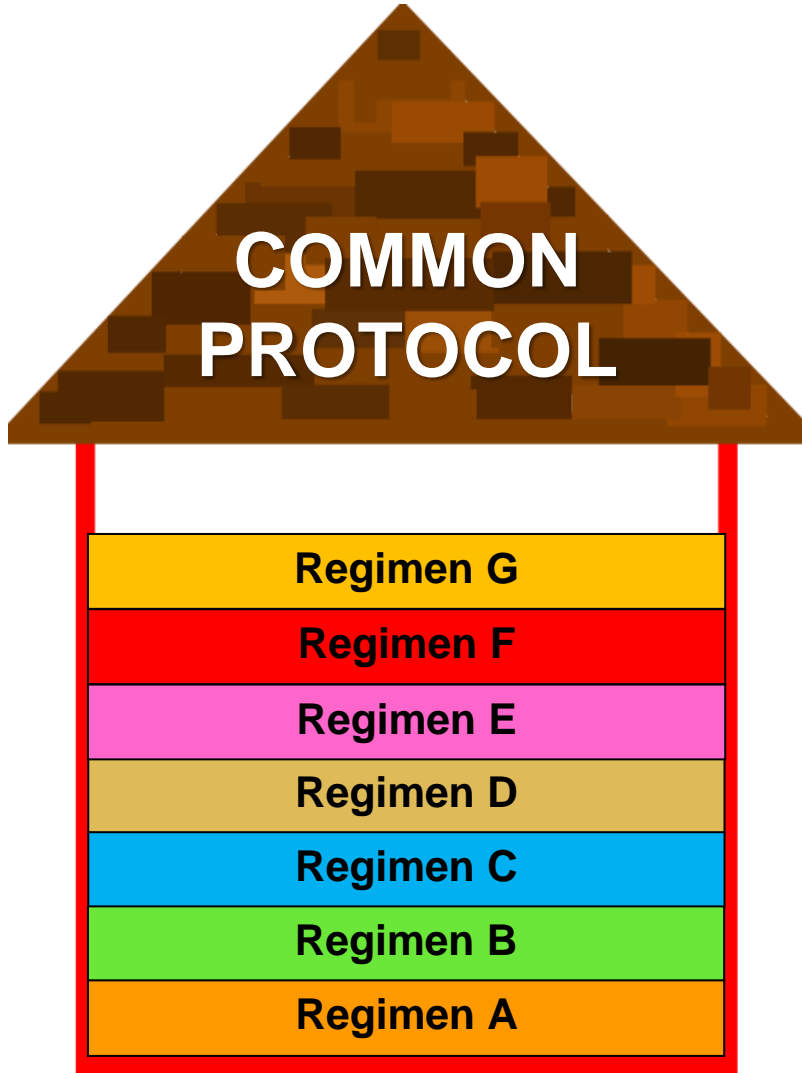
The AMG Foundation

Partnership, progress, and the pathway forward



ANNIVERSARY

Thank You

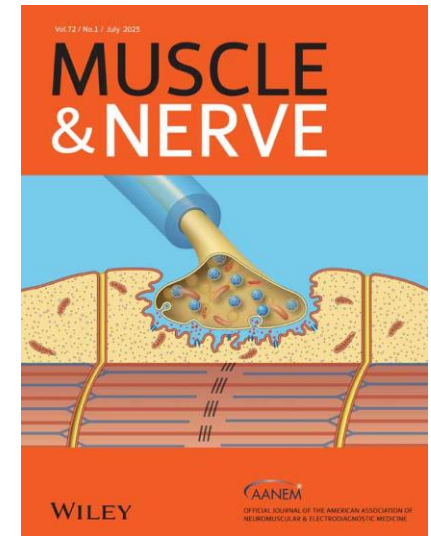


Sharing our learnings

Operational Development and Launch of an Adaptive Platform Trial in Amyotrophic Lateral Sclerosis: **Processes and Learnings From the First Four Regimens of the HEALEY ALS Platform Trial**

First published: 26 May 2025

Open Access



<https://onlinelibrary.wiley.com/doi/10.1002/mus.28442>

The HEALEY ALS Platform Trial is a perpetual, adaptive trial

NEWS · 5 MINUTE READ · DEC | 12 | 2024

Sean M. Healey & AMG Center Announces Updates to HEALEY ALS Platform Trial Master Protocol

View Press Release:



<https://bit.ly/4iKxSNO>

- The duration of the Randomized Controlled Trial (RCT) period is **extended from 24 to 36 weeks**
- The inclusion criteria were modified, with the **time since symptom onset now set at 24 months**
- The visit schedule has been made more streamlined and flexible, offering **increased opportunities for remote visits** in the Active Treatment Extension (ATE)
- **Thank you to our Patient Advisory Committee for invaluable feedback**

Acceleration Centers of Enrollment (ACE) Initiative

NEWS · 5 MINUTE READ · SEP | 4 | 2024

Sean M. Healey & AMG Center, Never Surrender, Inc. Establish Acceleration Center of Enrollment at University of Minnesota

View Press Release:



<https://bit.ly/3BhIYKg>

- The initiative will be led by a team of clinical investigators from Mass General, Northwestern and the University of Minnesota.
- Support for the ACE Initiative comes from an anonymous donor, ALS ONE, the **Les Turner ALS Foundation**, and Never Surrender.

NEWS · 5 MINUTE READ · AUG | 20 | 2024

Sean M. Healey & AMG Center for ALS and Les Turner ALS Center at Northwestern Medicine Establish Acceleration Centers of Enrollment Initiative

“By funding staff, training, and infrastructure, ACE is a vital step towards faster, more efficient research and ultimately, finding treatments and a cure for ALS.”

Jennifer DiMartino

Executive Director of ALS ONE

LES
TURNER
ALS
FOUNDATION



*Anne Marie Doyle, M.A., CCC-SLP
Director of Community Education
Les Turner ALS Foundation*

About Us

Leaders in comprehensive ALS care.

Founded in 1977, the Les Turner ALS Foundation is one of the longest-serving independent ALS groups in the country.

We are committed to providing the most comprehensive care and support to people living with ALS and their families so they can confidently navigate the disease, and advance scientific research for the prevention, treatment and cure of ALS.

How can a Les Turner ALS Foundation Support Services Coordinator help?



Answer questions about ALS



Emotional support



Recommendations for equipment to help with daily living, home safety, and more



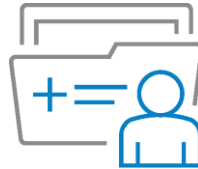
Provide equipment loans and need-based grant programs



Coordination with ALS care team



Resources about clinical trials and research



Guidance on Social Security Disability Insurance, Medicare, and Medicaid assistance with advanced directives



Guidance on caregiver assistance, facility options, and palliative and hospice care

Support Groups

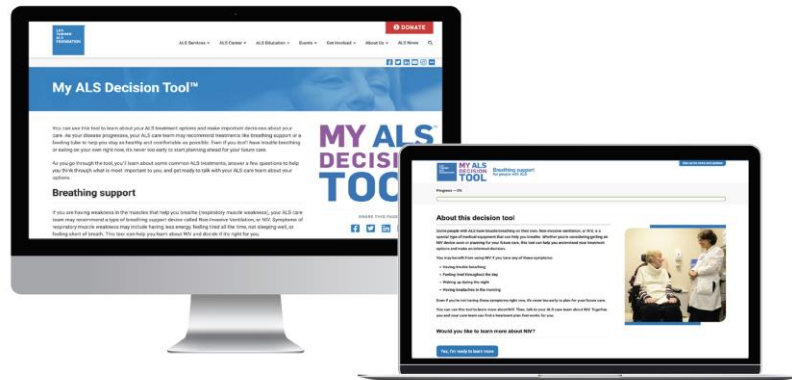
- The Les Turner ALS Foundation offers **free virtual support groups, open to people with ALS, caregivers, and those who have lost a loved one to ALS.**
- Peer support groups provide a **safe space to navigate the challenges of ALS** and help participants feel less isolated by connecting with others who share similar experiences.
- Groups are **led by professional facilitators** who provide guidance, education, and emotional support.
- There are specific groups for people **newly diagnosed, caregivers, and young adults**, as well as **bereavement groups** for those grieving a loss.



Online Education Tools

My ALS Decision Tool™ can help you choose ALS care that's in line with your needs and values. This interactive tool explains ALS treatment options and includes reflection questions to help you decide what's right for you.

**MY ALS
DECISION
TOOL**



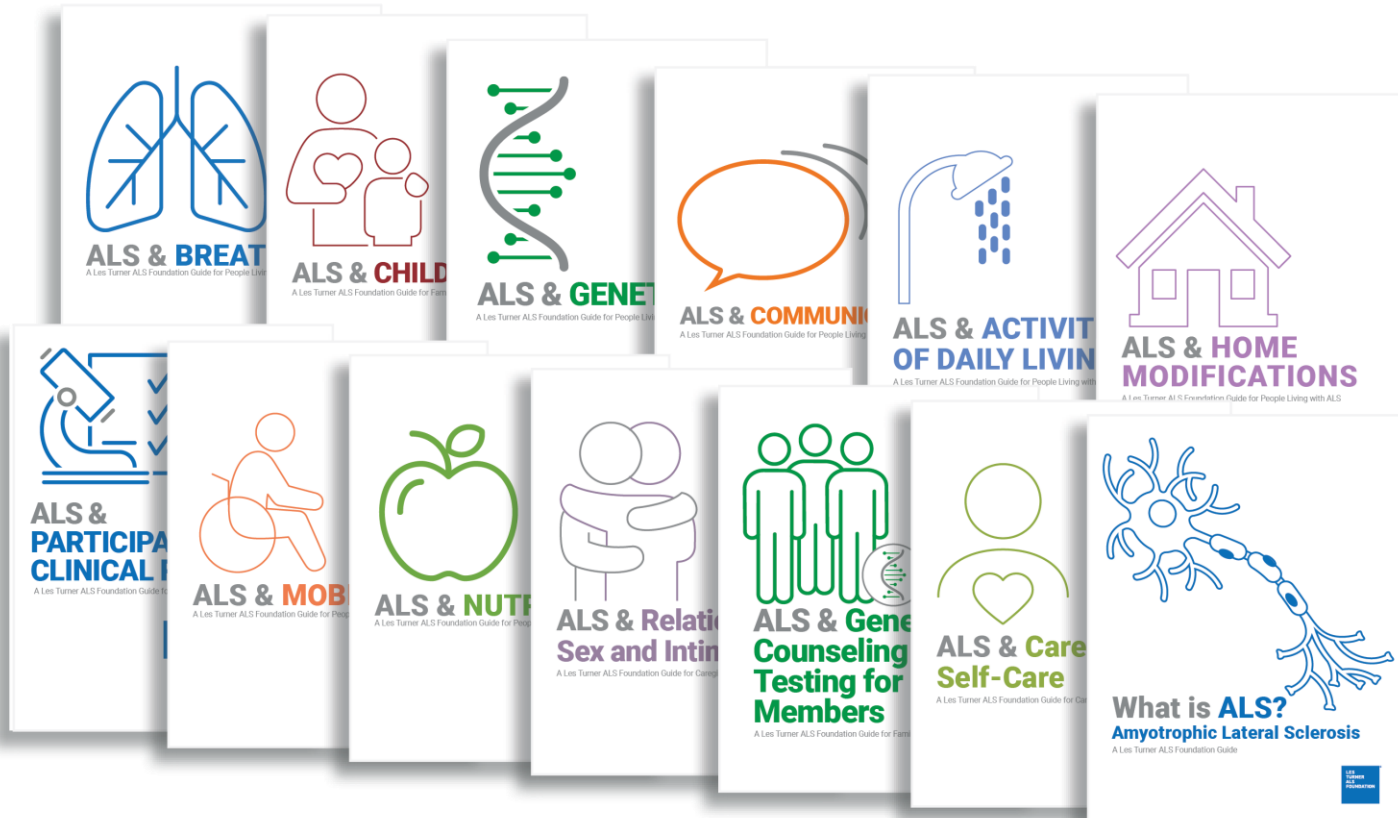
Current Modules:

- Non-Invasive Ventilation
- Feeding Tube
- Genetic testing for people living with ALS
- Genetic counseling and testing for family members ***New**
- Participation in ALS Clinical research ***New**



Online Guides

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Looking for in-depth information about **ALS symptoms and care options?** Les Turner ALS Foundation has you covered. We've created guides about key topics like nutrition, communication, mobility, and more.



ALS & Participation in Clinical Research

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ALS & PARTICIPATION IN CLINICAL RESEARCH

A Les Turner ALS Foundation Guide for People Living with ALS

Scan to view guide in English



ELA Y PARTICIPACIÓN EN INVESTIGACIONES CLÍNICAS

Una guía hecha por la Les Turner ALS Foundation para personas viviendo con ELA

Escanea para ver la guía en español



Genetic Resource Guides

Genetic testing for people living with ALS

All people living with ALS, regardless of clinical presentation or family history, **should have the option of genetic counseling and genetic testing.**

Genetic counseling and testing for family members

If you have a family history of ALS or a related neurologic condition — you may have questions like:
Am I at higher risk of developing this condition because of my family history?
Could my children/future children have a higher risk of developing this condition?

Genetic counseling can help you find answers.



People living with ALS



Family members



Educational Webinars



Covering a wide range of topics, the ALS Learning Series is designed to empower the ALS community through the latest information and insights from financial planning to respiratory care and more.

Voice Preservation Beyond Recording: Creating and Using My Preserved Voice

**Thursday, July 24, 2025,
12:00 p.m. CT**



Lane Rials from Bridging Voice will provide a comprehensive review of current best practices and tools in Message Banking, Voice Banking, and Voice Cloning, including the role of Artificial Intelligence (AI) in voice preservation. She will cover the full process from recording through integration, updates on current technologies, including AI's role in voice preservation, and treatment recommendations for using one's preserved voice most effectively and efficiently for functional communication.



ALS Clinical Research

Northwestern Medicine
Feinberg School of Medicine

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Les Turner ALS Center

- Biomarker studies
- Open-label therapeutic studies
- Natural history studies
- Clinical trials

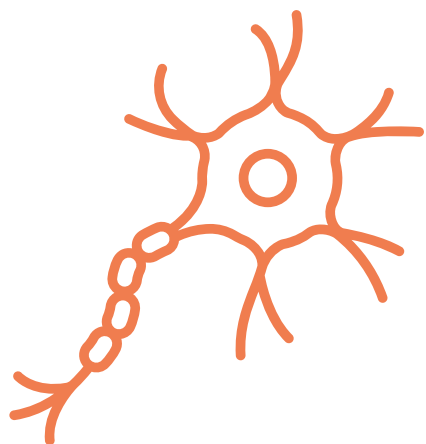


LTALSF Resources Available in Spanish

es.lesturnerals.org

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¿Qué es la
ELA?



Apoyo para
ELA



Cuidado e
investigación
de ELA



Educación
de ELA





Thank you to people living
with ALS and their families

LESTURNERALS.ORG
EDUCATION@LESTURNERALS.ORG
847 679 3311



5550 W TOUHY AVENUE
SUITE 302, SKOKIE, IL
60077-3254

Patient Navigation

Central resource for people living with ALS



Catherine Small

Phone: 833-425-8257 (HALT ALS)

E-mail: healeyalsplatform@mgh.harvard.edu

Two webinars
per month

Sign up for
ALS Link:



<https://bit.ly/3CqGbhb>

Register for
webinars:



<https://bit.ly/3r6Nd2L>

july 2025

SUN	MON	TUE	WED	THU	FRI	SAT
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6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

Upcoming Webinars (Thurs, 5:00- 5:30pm EST):

July 10 – Expanded Access Discussion with Dr. Rick Bedlack of Duke University

July 24 – Research Access Discussion with Judi Carey, RN of Mass General Hospital