

Thank you for joining the webinar!

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HEALEY ALS Platform Trial

Expanded Access Q&A – July 11, 2024



Healey & AMG Center

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



The AMG Foundation

Guest Speakers



Lauren Webb, LCSW



Chief Advocacy & Outreach Officer,
Les Turner ALS Foundation
EAP Patient Advisory Committee Member

Steve Kowalski



Research Ambassador & ALS Advocate
EAP Patient Advisory Committee Member



ALS & Participation in Clinical Research



ALS & PARTICIPATION IN CLINICAL RESEARCH

A Les Turner ALS Foundation Guide for People Living with ALS



Scan to view guide

<https://bit.ly/4eBi2mF>



ELA Y PARTICIPACIÓN EN INVESTIGACIONES CLÍNICAS

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



Escanear para ver la guía

<https://bit.ly/3xvKJ3T>



Online Guides



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 clinical research, nutrition, communication, mobility, and more.



Online Education Tools

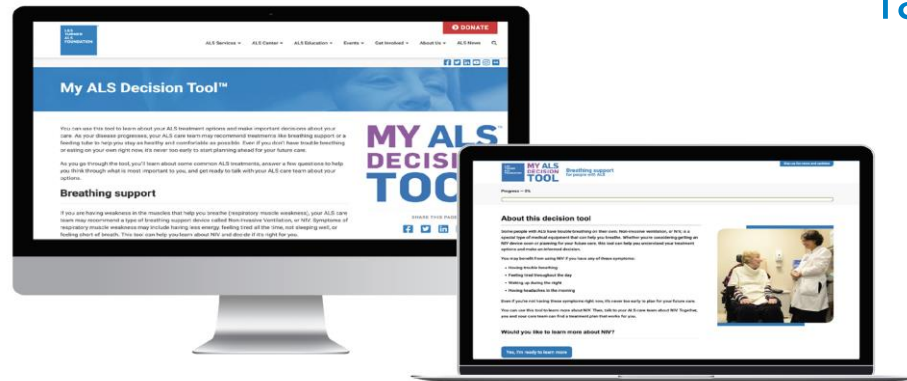


Current Modules:

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.

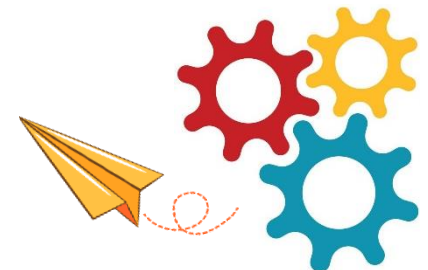
- Non-Invasive Ventilation
- Feeding Tube
- Genetic testing for people living with ALS
- Genetic counseling and testing for family members (new!)

MY ALS DECISION TOOL™



Clinical Trials, EAPs, and Lived Experience

- Key Takeaways: My clinical trial experience including participation in EAP
 - EAPs are programs run by trial sponsors that make experimental treatments available to pALS who do not qualify or cannot participate in a clinical trial
 - The ACT for ALS has increased access to investigational products for ALS by providing grants to help pay for EAPs
 - An EAP can be run for a single patient, a small group of patients, or groups of hundreds or thousands of patients
 - pALS may request an EAP through their doctor – but companies have no obligation to grant these requests



EAP Patient Advisory Committee

- Key Takeaways: As a member of the Healey EAP Patient Advisory Committee
 - The growth of EAP sites and access has been steady over the past several years
 - EAPs are costly on a per patient basis and ongoing funding is needed for sustainability
 - Building a network of sites takes time and resources due to high level of awareness and training at locations where pALS receive medical care
 - Some EAPs may contribute to ALS research by providing safety and biomarker data
 - Enrollment awareness and process improvement within the ALS community is an ongoing top priority and can be challenging on a site-to-site basis
 - The goal? A streamlined, seamless enrollment process.



Expanded Access Resources and Webinar Opportunities

Join us for updates about Expanded Access and EAPs **on the second Thursday of each month!**

(or view recordings online)



<https://bit.ly/43GuegQ>

Visit the NEALS website to explore upcoming educational webinar opportunities or view previous recordings



<https://bit.ly/3S4P0Sb>

Find more webinar opportunities and recordings through the **International Alliance of ALS/MND Associations**



<https://bit.ly/3Obj2m6>

Patient Navigation

Central resource for people living with ALS



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Weekly webinar
registration:



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

ALS Link sign-up:



<https://bit.ly/3o2Ds3m>

Summer Series Upcoming Webinars:

July 25th- Monthly Platform Trial Update featuring Dent Neurologic Institute (NY)

August 8th- Monthly EAP Webinar

August 22nd- Monthly Platform Trial Update



Allison Bulat