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.
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

Scan to view guide
https://bit.ly/4eBi2mF

ELA Y PARTICIPACIÓN EN INVESTIGACIONES CLÍNICAS

Escanear para ver la guía
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

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.

Current Modules:

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

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

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

https://bit.ly/43GuegQ

https://bit.ly/3S4P0Sb

https://bit.ly/3Obj2m6
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

Patient Navigation
Central resource for people living with ALS

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