

I AM ALS presents the Genetic ALS Observational Studies Dashboard

A patient-created online dashboard of pre-symptomatic ALS research studies to better connect potential trial participants and the scientific community

Background

- Through frequent meetings with the scientific research community, the Familial ALS Community Team (fALST) - part of the patient-led organization I AM ALS - discovered that asymptomatic ALS research studies often have difficulty connecting with prospective study participants, significantly prolonging a study's time to completion.
- Pre-symptomatic gene carriers are hard to reach since they typically do not begin interacting with the ALS medical community until the onset of ALS symptoms.
- The ALS patient community was concerned that partially filled or slow-to-fill research studies may delay scientific progress and lead to reduced investment in future ALS research due to lack of adequate data points, both of which could be an impediment to finding a cure.
- Per industry research, the challenge of securing participants primarily stems from identifying an at-risk population and resolving various logistical and ethical considerations [1].

Objective

- The fALST interviewed numerous principal investigators, as well as both active and former pre-symptomatic study participants, to identify ways to better match supply and demand with the intent of accelerating the time to conclude pre-symptomatic studies.
- The preliminary findings concluded that study participants (supply) were most concerned with ethical and logistical study data points:
 - Whether the study included genetic counseling, their gene status would be documented in their medical records.
 - The study-related travel costs would be covered, and the length and frequency of study visits would be feasible for them.
 - Principal investigators and research coordinators (demand) were seeking ways to reach a wider audience within the difficult-to-reach pre-symptomatic ALS community, while having better upfront screening for potential study eligibility and interest.

Results

- The result was the creation of the newest addition to ALS Signal, a browsable online dashboard that contains pre-symptomatic research studies and the ability to filter each based on key attributes, such as:
 - Whether genetic counseling is included.
 - Whether travel reimbursement is provided.
 - Where the study is geographically located.
 - How long the study is to occur.
- Study information is either provided directly by the research coordinator, pulled from clinicaltrials.gov, or obtained directly from the research study's primary website.
- The dashboard is reviewed by the scientific advisory panel at I AM ALS to ensure it is eligible to be recommended by the medical community to their patients.
- The dashboard has received positive feedback from both patient and medical communities and has potential to accelerate the conclusion of pre-symptomatic research studies with the objective of more quickly finding a cure for ALS.

Figure 1: First page of Genetic ALS Dashboard

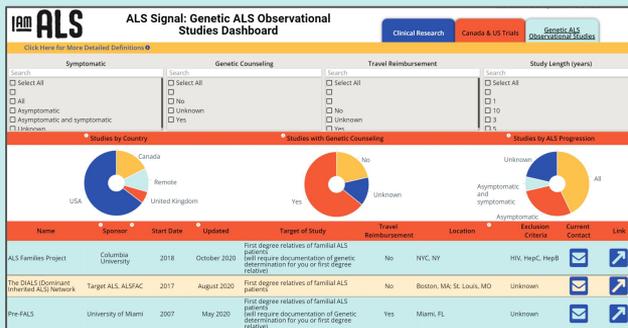


Figure 2: Online form to submit a study for inclusion

Familial ALS - Research Study Submission Form

Use this form to submit actively recruiting Familial ALS research studies that are not already listed in the I AM ALS Signal Portal

What is the name of the research study? *

Short answer text

Who is the best person for I AM ALS to contact to learn more about the research study?

Short answer text

The form can be found at www.tinyurl.com/alsresearchdashboard

Conclusion

- The fALST concluded the creation of a user-friendly online dashboard of pre-symptomatic studies containing key attributes could significantly assist in matching potential research participants with ongoing and future research studies.

Authors

- Glasgow J., Mapes V., Swidler J., Chase, MSN, ANP-BC, J. supported by the I AM ALS organization

References

- 1. Benatar, Michael & Wu, Joanne. (2012). Presymptomatic studies in ALS Rationale, challenges, and approach. Neurology. 79. 1732-9. 10.1212/WNL.0b013e31826e9b1d.