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

ALS	ALS	Signal: St	Genetic A udies Das	LS Observational shboard	Clinica	I Research Canada & US	Trials Observation	tic ALS inal Studies	
Click Here for More	Detailed Definitions 4)							
Symptomatic		Genetic Counseling			Travel Reimbursement		Study Length (years)		
Search		Search		Search		Sean			
□ Select All □ All		Selec	t Ali	□ Select	All	D Se	lect All		
D AII		□ No		H		l in			
☐ Asymptomatic		□ Unkr	iown	□ No		D 10			
☐ Asymptomatic and sym ☐ Lloknown	ptomatic	☐ Yes		☐ Unkni	own	D3			
		-		□ Yes		i ns	_		
	Studies by Country			Studies with Genetic	Counseling		Studies by ALS I	Progression	
USA	G	Remote United Kingdo	om	Ye	Vinknown	Asympto and symptor		A	
Name	Sponsor	Start Date	Updated	Target of Study	Travel Reimbursement		Exclusion Criteria	Current	Link
				First degree relatives of familial ALS patients					
NLS Families Project	Columbia University	2018	October 2020	patients (will require documentation of genet determination for you or first degree relative)	ic No	NYC, NY	HIV, HepC, HepB		7
The D(ALS (Dominant nherited ALS) Network	Target ALS, ALSFAC	2017	August 2020	First degree relatives of familial ALS patients	No	Boston, MA; St. Louis, MO	Unknown		7
re-FALS	University of Miami	2007	May 2020	First degree relatives of familial ALS patients half require documentation of Genet determination for you or first degree	ic Yes	Miami, FL	Unknown		7

Figure 2: Online form to submit a study for inclusion

Fami	lial ALS - Research Study Submission Form
Use this for ALS Signal	rm to submit actively recruiting Familial ALS research studies that are not already listed in the I AM Portal
What is the	e name of the research study? * er text
Who is the	a best person for I AM ALS to contact to learn more about the research study?

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 & Wuu, Joanne. (2012). Presymptomatic studies in ALS Rationale, challenges, and approach. Neurology. 79. 1732-9. 10.1212/WNI.0b013e31826e9b1d.

