

*The ALS Association*  
**CONFIDENTIAL**



# VIRTUAL ALS ROUNDTABLE EXECUTIVE MEETING SUMMARY

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**April 23, 2020 and May 13, 2020**

# OVERVIEW

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## ALS ROUNDTABLE OVERVIEW

**T**he ALS Association convened its first-ever Virtual ALS Roundtable on April 23 and May 13, 2020. At the roundtable, 69 participants representing key ALS stakeholders (see Appendix C) mapped out key challenges and solutions for reducing time to diagnosis for people with ALS. This issue was a priority identified at the Association’s March 2019 Roundtable.

The Roundtable provided an opportunity for collective brainstorming and problem solving about the challenges, potential solutions, and near-term action steps the community can take to streamline and accelerate the process of arriving at an ALS diagnosis. The objectives for the Roundtable were to identify several highest priority challenge and solution topic pairs, which will be used to design scope of work and project road maps for working group efforts that will be launched by the Association in June 2020.

Roundtable participants included people living with ALS and their caregivers, ALS physicians and other health care providers, representatives of industry, and Association leadership actively engaged in discussion and problem solving. Both meeting days were facilitated by Ilisa Halpern Paul, President of the District Policy Group at Faegre Drinker.

A highlight of the Roundtable was the opening panel session on April 23, which featured personal stories from people impacted by ALS. In briefly describing their diagnostic journeys, three people living with ALS and one caregiver of a family with

inherited ALS spoke poignantly about their experiences and identified key issues for the Roundtable participants to address.

## ALS ROUNDTABLE CONTEXT

During the plenary session on April 23, ALS Association Chief Mission Officer Neil Thakur, Ph.D., provided context for this effort and traced the groundwork for the reducing time to diagnosis topic to the organization’s first Roundtable in March 2019, at which it ranked as the top priority in both pre-meeting and post meeting surveys. Conversations and presentations at the October 2019 Northeast ALS Consortium (NEALS) meeting reinforced the high interest and concern about this topic among the ALS clinician and researcher community. There was also consensus around the importance of this topic among members of the Association’s Roundtable Advisory Panel.

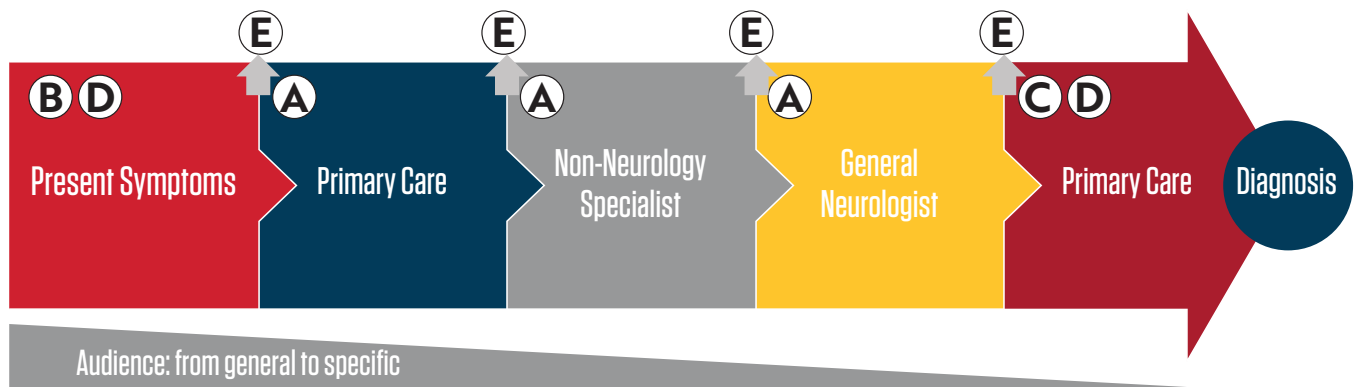
Vice President of Mission Strategy Jill Yersak, Ph.D., set the initial foundation for the group’s discussion by reviewing the system challenges (from the physician, patient, and caregiver perspective) and science challenges (involving measuring and tracking diagnosis) to ensure timely diagnosis. She also discussed time to diagnosis considerations for inherited (genetic) ALS that involves genetic testing and counseling.

The first day of the Roundtable (April 23) culminated in three multi-stakeholder breakout sessions during which participants assessed impact and feasibility for solutions relating to reducing time to diagnosis.

Following the three breakouts, the Association staff created a master list of challenges and solutions, noting consensus across the groups.

Using this consensus framework, the Association surveyed participants asking them to prioritize eight challenge-solution pairs delineated by target audiences (see pyramid diagram) and based on impact

and feasibility. The survey focused on the following challenge-solution pairs, their relevance across the ALS diagnostic journey experience, and the specific audiences that could be targeted for actionable solutions (see diagram and list below). The survey results were compiled and analyzed in advance of the second meeting to inform the discussion on May 13.



### Topic A:

**CHALLENGE:** Lack of awareness and training of physicians (primary care providers, non-neurology specialists or general neurologists) to identify the signs and symptoms of ALS; Resistance to make a diagnosis.

**SOLUTION:** Improve and expand the ability of physicians (primary care providers, non-neurology specialists or general neurologists) to make a diagnosis.

### Topic B:

**CHALLENGE:** Lack of understanding the signs and symptoms of ALS of the general public or those with ALS in their families; Denial or fear of diagnosis of people who may be diagnosed.

**SOLUTION:** Increase education and awareness and help improve receptivity to a potential diagnosis.

### Topic C:

**CHALLENGE:** Limited access to ALS specialists.

**SOLUTION:** Increase capacity of and access to ALS clinics.

### Topic D:

**CHALLENGE:** Lack of genetic testing and counseling for patients with inherited ALS.

**SOLUTION:** Increase awareness and access to genetic testing and counseling.

### Topic E:

**CHALLENGE:** Lack of an electronic system and limited availability of other digital tools to detect the signs and symptoms of ALS and to help prevent mistakes in the diagnostic journey.

**SOLUTION:** Develop methods and measures to best detect and prevent mistakes in the diagnostic journey.

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