



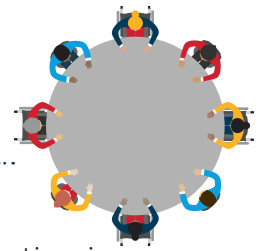
Executive Summary

ALS ASSOCIATION ROUNDTABLE

March 29, 2019

CONFIDENTIAL — THE ALS ASSOCIATION

OVERVIEW



On March 29, 2019, The ALS Association convened its first roundtable meeting in Washington, D.C. Thirty-seven participants, representing key ALS stakeholders, attended. (See Appendix B for meeting participants.) ALS Association President and CEO Calaneet Balas laid out the purpose for the discussion, which was to provide input to the Association in setting its strategic priorities for the next 3-5 years and help define the best use of resources to help people living with ALS now and in the future.

The meeting offered an intimate and facilitated day-long discussion with key partners, academia, people living with ALS, caregivers, regulatory officials, industry representatives, and ALS Association leadership.

Topics for detailed discussion included: improving time to diagnosis, alleviating caregiver burden and enhancing home health options. These topics were determined in advance in a pre-meeting survey taken by our roundtable participants. The group collectively defined the key challenges in each of these areas, proposed solutions, and identified program opportunities for the Association and its partners. Additional topic areas were also addressed, including the need for research progress, biomarker identification, clinical trial participation, lessening financial impact, and developing a Clinical Records Repository/Patient Portal. (See Appendix A for meeting agenda.)

At the conclusion of the meeting, the single biggest priority that we identified was reducing time to diagnosis. Increasing clinical trial participation also came to the forefront. The other earlier identified top areas also remained high priority.

These priority areas will now become key to the Association's leadership discussions and strategic planning so that a detailed strategic implementation plan will be formed clearly outlining next steps and outcome measures that will be achieved.

BACKGROUND

In preparation for the March 29 roundtable, The ALS Association surveyed participants from across the ALS ecosystem, including people living with ALS, caregivers, board members, leaders in academia and clinical care, regulatory colleagues, and industry partners to identify priority topic areas for community focus in the near term. The survey was conducted via email, with results summarized in Appendix C.

The top three topics from the survey — improving time to diagnosis, alleviating caregiver burden, and enhancing home health — became the focal points for the roundtable agenda. Each topic was summarized and described in pre-read materials sent to all participants. ALS Association Executive Vice President for Mission Strategy, Dr. Neil Thakur briefly reviewed the survey effort at the outset of the meeting discussion.

All participants had the opportunity to introduce themselves and provide brief comments

about their participation.

The meeting was facilitated by Ilisa Halpern Paul, of District Policy Group, who encouraged all participants to be candid and open in providing their feedback to ensure that all perspectives were presented and considered. For each major agenda topic, the discussion was broken down into three sections: unpack the problem, identify solutions, and define next steps.

KEY TAKEAWAYS

There are many gaps and needs for the ALS community that require near-term and medium-term solutions. Roundtable participants evaluated three significant topics of concern and prioritized action among them through an iterative process of discussion and group voting exercise. What emerged from this effort was consensus that reducing time to diagnosis is the highest priority area for near-term focus, followed by an emphasis on increasing participation in clinical trials. Frequent themes from throughout the day included:

- Importance of driving new science for ALS (including emphasis on biomarkers and research on sporadic disease).
- Identifying triggers for consideration of ALS diagnosis.
- Necessity of gathering and disseminating data on the burden of ALS (especially for caregivers).
- Need to expand coverage and reimbursement for ALS (holistic approach).
- Emphasis on workforce education and training (including neurologists, front-line service providers, and home health).
- Public education and awareness, especially within at-risk populations.

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