

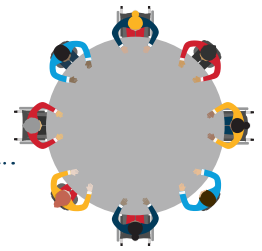


# ALS ASSOCIATION ROUNDTABLE MEETING ON ESSENTIAL CARE, SERVICES, AND SUPPORTS

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May 6-7, 2021

# OVERVIEW



## ALS ASSOCIATION ROUNDTABLE PROGRAM OVERVIEW

**O**n May 6 and 7, 2021, The ALS Association (the Association) convened our fifth multi-stakeholder Roundtable. This meeting focused on ensuring access to essential care, services, and supports for people living with ALS and their caregivers. The roundtable met virtually over two consecutive half-days, with more than 85 people participating in an extended plenary session on day one and a total of three small-group break-out sessions on day two.

The topic of access to essential care, services, and supports has come up frequently in a variety of ways during previous Roundtable meetings, prompting the decision to structure a full Roundtable agenda around its many facets. As the Association previously held a Roundtable session on ensuring access to new therapies, our goal with this meeting was to focus on the other aspects of care – clinical care, care services (e.g., in-home non-medical care), as well as physical supports (e.g., durable medical equipment and home modifications), and non-physical supports (e.g., financial, mental, and emotional).

During the first day, participants heard from people living with ALS, caregivers, and case workers about the challenges and gaps associated with accessing care, services, and supports; health policy experts who provided baseline information on the range of health insurance plans and what they mean for people with ALS; a panel presentation on what the Veterans Health Administration (VHA) provides



to people with ALS; and ALS national office staff about projects that are underway to support individuals and families throughout their ALS journey. During the small group sessions on the second day, stakeholders enumerated the most significant gaps and identified priority areas for the Association to address either through advocacy, care services, education, and/or philanthropy.

Focusing on key topics of relevance to the ALS community in a multi-stakeholder format aimed at solutions is groundbreaking. Roundtable discussions are always enlightening and intense, helping to shine a focused spotlight on areas of greatest need for people living with this disease.

Since launching in 2019, the Roundtable Program has regularly assembled members of the ALS community for candid, facilitated discussions about issues of priority to people with

ALS, helping shape the Association's strategic planning efforts, and identifying action steps to improve ALS care, advocacy, and research. Roundtable meetings convene a diverse group of individuals reflecting a range of ALS expertise and experiences, including people living with ALS, caregivers, clinicians, researchers, government officials, and industry partners.

While the Roundtable Program launched with in-person gatherings, the COVID-19 pandemic prompted the most recent Roundtable sessions to "go virtual." Though the format has changed, there continues to be a high level of engagement, participation, and productivity among participants.

2021 Roundtable Program sponsors include: Alexion, Amylyx, Apellis Pharmaceuticals, Biogen, Biohaven Pharmaceuticals, Cytokinetics, Helixmith, Ionis Pharmaceuticals, Mitsubishi Tanabe Pharma America, Novartis Gene Therapies, Orphazyme, and UCB. The meeting was facilitated by Ilisa Halpern Paul, president of the Faegre Drinker District Policy Group. The discussion was also shaped by contributions from multiple people with ALS and their caregivers, to whom we are extremely grateful for contributing their time and insights and sharing their personal experiences and lessons learned during their journey.

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