



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

Fundamental Rights: Access to Care June 2024 Roundtable Meeting Summary

Contents

Executive Summary..... 3

Attendees 3

Agenda 5

Opening Comments..... 5

Presentations..... 9

Group Discussions 12

Next Steps 13

Executive Summary

On June 13, 2024, a multi-stakeholder group of 32 individuals, representing various communities within the International Alliance of ALS/MND Associations' network, gathered for a Roundtable focused on the second of the Alliance's Fundamental Rights for Persons Living with ALS/MND: Access to Care.

Not all countries are able to meet the basic needs of people living with ALS/MND or there may be limited availability and access to care. Even in countries with more advanced healthcare systems, within the current access environment, each country or geography has its own processes for investing in, approving, and making a range of services necessary for optimal care available. The Roundtable discussion was designed to help provide an understanding of the challenges regions and jurisdictions face in ensuring access to care, and what tools they need to help with their efforts.

The meeting included an opening plenary and two group discussions. During the plenary session, participants heard a series of brief expert presentations designed to describe the full continuum of services under the umbrella of "care" for a person living with ALS/MND and their caregivers. The participants explored the economic burden of care and the impact of motor neuron disease on families. The session concluded with discussions on the World Health Organization's Global Action Plan for neurological disorders as well as opportunities with telemedicine to support effective management of neurological conditions.

Key outcomes of the meeting include deeper understanding among participants of gaps and barriers to care access for people living with ALS/MND and their caregivers across various geographies, calls to action to promote global capacity for telemedicine/telehealth and policy changes to support enhanced access to care, and a short list of priority programs for the Alliance and its member associations to advance in supporting increased access to care in all parts of the world.

Attendees

Meeting participants included representatives from multiple global ALS/MND organizations, members of the Alliance's staff and PALS and CALS Advisory Council (PCAC), industry officials and invited expert speakers. All sessions were facilitated by Wendy Selig, Founder and CEO of WSCollaborative, and sponsorship support for the Roundtable was provided by Mitsubishi Tanabe Pharma and Sanofi.


Attendee Roster - Discussion Group 1			
Last Name	First Name	Affiliation	Country
Balas	Calaneet	The ALS Association (ALSA)	USA
Barajas Azpeleta	Raquel	Fundación Luzón	Spain
Bedlack	Richard	Duke University (Presenter)	USA
Burn	Kevin	Irish Motor Neurone Disease Association	Ireland
Conte	Silverio	Associazione conSLancio Onlus	Italy
Cook	Claudine	ALS Quebec	Canada

Cummings	Catherine	The International Alliance of ALS/MND Associations	Canada
de Majo	Martina	The International Alliance of ALS/MND Associations	Italy
Dua	Tarun	World's Health Organization (Presenter)	Switzerland
Dupont	Melissa	Sanofi	USA
Filic	Ivona	Mitsubishi Tanabe Pharma America	USA
Finning	John	Mitsubishi Tanabe Pharma America	USA
Hjelle	Jennifer	The ALS Association (ALSA)	USA
Kavanaugh	Melinda	Global Neuro YCare	USA
Kaya	Alper	ALS/MND Association Türkiye	Turkey
LANGAT	Philip	MNDA Kenya	Kenya
Mabe	Jessica	The International Alliance of ALS/MND Associations	Colombia
Selig	Wendy	WSCollaborative (Facilitator)	USA
Simon	Julia	The International Alliance of ALS/MND Associations	Canada
Tran Minh Duc	Nguyen	ALS Vietnam	Vietnam
Ulgenalp	Ilayda	ALS Society of Canada	Canada
Virgo	Bruce	PALS and CALS Advisory Council (PCAC)	Scotland

Attendee Roster - Discussion Group 2			
Last Name	First Name	Affiliation	Country
Ali	David	The International Alliance of ALS/MND Associations	Australia
Calderón-Castro	Andrea del Pilar	Hospital Universitario Nacional de Colombia	Colombia
Cummings	Catherine	The International Alliance of ALS/MND Associations	Canada
Lewin	Stacy	PALS and CALS Advisory Council (PCAC)	USA
Mabe	Jessica	The International Alliance of ALS/MND Associations	Colombia
MacIsaac	Norman	PALS and CALS Advisory Council (PCAC)	Canada
Selig	Wendy	WSCollaborative (Facilitator)	USA

Sklavenitis	Leanne	PALS and CALS Advisory Council (PCAC)	Australia
Thomas	Gethin	Motor Neurone Disease Australia	Australia
Yap	Min	FightMND	Australia

Agenda

			
<p>Fundamental Rights: Access to Care June 13, 2024</p>			
Agenda Overview		Agenda Detail	
Plenary Session	Virtual	Plenary: Thursday June 13: 7:00-8:30am ET (New York)	
	June 13, 2024: 7:00am-8:30am ET New York		
Group Discussion	Virtual		
	Group 1; June 13, 2024; 9:00am-10:30am ET (New York)		
	Group 2; June 13, 2023; 7:00pm-8:30pm ET (New York)		
Description	<p>Access to the highest quality care available is a fundamental right for people living with ALS/MND. Here are some shocking key facts from the World Health Organization:</p> <ul style="list-style-type: none"> Improvements to health services coverage have shown no significant progress since 2015. Approximately 2 billion people are encountering financial difficulties, with 1 billion undergoing severe out-of-pocket health expenditures, or 344 million people slipping further into extreme poverty as a result of health-related expenses. <p>This roundtable will provide a foundation to a global understanding of how access to care is respected in different parts of the world.</p> <p>The discussion will help identify priority areas for the Alliance, what ALS/MND associations can do at a local level, and who else needs to be involved to help change happen.</p>	<ul style="list-style-type: none"> Contextual overview Cathy Cummings Global headlines Bruce Virgo & Leanne Sklavenitis Economic burden of caregiving Dr. Caroline Ingre Burden of ALS/MND on the family upon diagnosis Dr. Melinda Kavanaugh & Dr. Priya Thomas Addressing the gap in social sciences Dr. Tarun Dua WHO Global Neurology Action Plan Dr. Richard Bedlack Telehealth Questions Wrap up & Discussion group instructions 	
		Group Discussion	
		Virtual: Thursday, June 13: Group 1: 9-10:30am ET: Group 2: 7-8:30pm ET	
		Debrief from Plenary	
		Facilitated Discussion:	
		<ul style="list-style-type: none"> What are the capacity and infrastructure gaps in your region? Where can we collaborate to level access to care? Who are the key stakeholders to make change happen? What are the highest priority action steps the Alliance can take? What are the highest priority action steps associations can take? 	
		Wrap up and Next Steps	

A summary of the discussion during the Access to Care Roundtable meeting is embedded in the document that follows.

Opening Comments

Alliance CEO Cathy Cummings provided the background and context for the Roundtable, which is the second of a series that will be focused on individual components of the Alliance's Fundamental Rights for People Living

with ALS/MND. These include the rights to the highest quality treatments available, information and education, choice regarding end-of-life care, provide input into surrounding systems, live without discrimination, confidentiality and privacy, available remuneration, and access to genetic counselling and testing.

People living with ALS/MND have the right to:

1. The highest quality **treatments** available.
2. The highest quality **care** available.
3. **Information and education** that will enable them to play an active role in making decisions.
4. **Choice** with respect to:
 - I. health and support workers who are providing treatment or advice;
 - II. the location where care takes place; and
 - III. the type of treatment or support that is provided.

People living with ALS/MND have the right to:

- 5) **End-of-life choices**, which include the right to accept, refuse or discontinue treatment or intervention within the legal framework of their own country.
- 6) **Provide input** on the healthcare and support systems, including policy-making, care delivery, and the implementation of medical research procedures and protocols.
- 7) The liberty to live the **best quality of life** possible.
- 8) Live without **discrimination**.

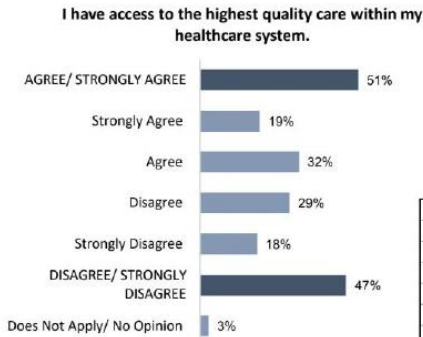
People living with ALS/MND have the right to:

- 9) **Confidentiality and privacy** regarding their personal information.
- 10) Receive any available governmental or other economic **remuneration**, benefits and entitlements.
- 11) Have **access**, upon diagnosis (or likely diagnosis), to:
 - I. up-to-date education about **clinical genetics** in ALS/MND;
 - II. **genetic counselling**;
 - III. **genetic testing**;
 - IV. safeguards against **genetic discrimination**; and
 - V. subject to education and counselling, **blood relatives** should also be given the same access, where relevant.

The Alliance surveyed its global constituents in 2021 and again in 2023, when almost 2,000 participants in 54 countries responded. The 2021 survey provided an initial baseline from which the 2023 survey results could be evaluated.

With respect to access to care, it was noted that the term “care” is used broadly to refer to a whole array of services and specialists that are needed by people living with ALS/MND and their caregivers. Overall, responses indicated greater perceived access to care in the “Global North” of the world than the “Global South”, and English-speaking countries generally had higher positive responses than non-English-speaking countries regarding access to treatments. Results showed varying levels of perceived access to care, with concerns about disparities and uncertainty in some regions. Top line “universal truths” that emerged from the survey were the high proportion of caregivers that are female, the significant economic impact of ALS/MND, and the lack of mental health support.

Data Views – Agreement; Filters; Countries



	2023		2021		Global N vs S		English		Urban		Asia-Pacific	
	%	N	%	N	North	South	Yes	No	Urban	Rural	Yes	No
TOTAL RESPONDENTS	900	900	408	408	640	260	230	670	727	166	315	585
Agree/ Strongly Agree	51%	455	49%	198	59%	30%	82%	40%	49%	58%	46%	53%
Strongly Agree	19%	171	22%	88	23%	8%	40%	12%	18%	23%	17%	20%
Agree	32%	284	27%	110	35%	22%	42%	28%	31%	35%	29%	33%
Disagree	29%	258	25%	103	23%	43%	12%	34%	30%	22%	30%	28%
Strongly Disagree	18%	163	24%	96	16%	23%	5%	23%	18%	17%	22%	16%
Disagree/ Strongly Disagree	47%	421	49%	199	39%	67%	17%	57%	49%	39%	51%	44%
Does Not Apply/ No Opinion	3%	24	3%	11	2%	3%	1%	3%	2%	4%	3%	3%

	2023	Country										
	%	TUR	BRA	ESP	USA	AUS	CAN	COL	JPN	NLD	DNK	KOR
TOTAL RESPONDENTS	900	174	136	83	80	60	51	43	42	36	28	29
Agree/ Strongly Agree	51%	22%	20%	40%	94%	92%	82%	49%	64%	83%	68%	66%
Strongly Agree	19%	5%	4%	13%	44%	53%	39%	14%	14%	33%	25%	14%
Agree	32%	17%	16%	27%	50%	38%	43%	35%	50%	50%	43%	52%
Disagree	29%	40%	52%	30%	4%	5%	12%	35%	29%	6%	21%	31%
Strongly Disagree	18%	34%	27%	28%	3%	3%	6%	14%	7%	8%	4%	3%
Disagree/ Strongly Disagree	47%	74%	79%	58%	6%	8%	18%	49%	36%	14%	25%	34%
Does Not Apply/ No Opinion	3%	3%	1%	2%	0%	0%	0%	2%	0%	3%	7%	0%

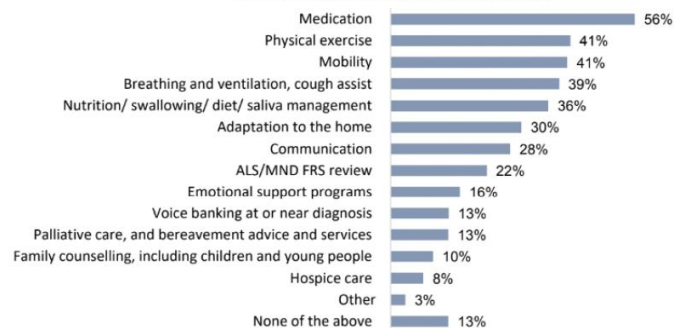
Specialist Care

I receive care from:



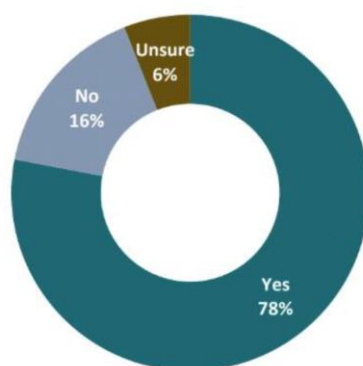
Receiving Support

I receive support in the following areas:



Economic Situation Affected by ALS/MND

Has ALS/MND affected your economic situation?



Specific points from the survey related to access to care include:

- 51% of respondents agree or strongly agree they have access to high-quality care.
- The global average for respecting patient rights is 52%.
- Only 40% of caregivers agree they have access to all their rights.
- Caregiver rights include counseling, emotional support, time for themselves, bereavement advice, future planning, information access, training, resources, remuneration, and advocacy.
- 46% have access to a multidisciplinary clinic, with 64% finding it easy to get to the clinic.
- Common specialists include neurologists and physiotherapists; genetic counseling is less accessible.
- Mental health support is notably low.
- 74% can receive care in their preferred language.
- High access to medication and physical exercise support; low access to hospice care, family counseling, and palliative care.
- High-quality care correlates with access to various specialists and services, including occupational therapists, speech therapists, and genetic counselors.
- 66% have access to an ALS/MND association, which correlates with higher quality care.
- 55% have no paid caregivers.
- Caregivers face significant economic impacts, with 78% reporting financial strain.
- A high proportion of caregivers are female, and there is a notable lack of mental health and social support services for caregivers.

Participants saw an abbreviated video with testimonials from key global ALS/MND stakeholders describing needs, gaps, challenges, and opportunities with respect to access to care. The full video was provided to participants as part of the pre-read materials for the Roundtable.

[Watch the “Global Headlines Access to Care” video.](#)

Presentations

Bruce Virgo and Leanne Sklavenitis described their experiences living with ALS/MND and their ability to access the care they need, focusing on the economic burden of living with ALS/MND and accessing needed caregiving support. Bruce described the significant direct and indirect costs associated with an ALS/MND diagnosis, including medical and equipment expenses, home modifications, professional caregiving, loss of income for the person with ALS/MND and their family caregivers, time costs, opportunity costs, psychological impact (stress, burnout, isolation), and impact on family dynamics and sense of security.

Leanne described her personal situation, highlighting the financial and emotional strain the disease placed on her and her husband, who left his job to become her full-time carer before the burden became too great and they needed to employ a team of professional carers. While expressing gratitude for the ability to receive government financial support, she also discussed the challenges she faced accessing Australia's National Disability Insurance Scheme (NDIS), the high cost of equipment and resources to allow her to continue living her best life despite the ravages of ALS/MND, and the feeling of vulnerability knowing that she is totally dependent on a government program for support.

Dr. Caroline Ingre provided an overview of the burden on families that comes with an ALS/MND diagnosis, including the impact on children, spouses, siblings, and parents of people living with the disease. She noted that in Sweden, where care is universally accessible without the need for insurance, doctors (as opposed to associations) are generally the ones advocating for patients. There is high accessibility to competent care, with an emphasis on shared decision-making between patients and doctors. ALS/MND is a family disease, impacting not just the patient but the entire family, necessitating comprehensive support and care. There is significant data in the literature about the impact of an ALS/MND diagnosis on children of ALS/MND patients, many of whom are vulnerable and facing higher risks of depressive symptoms. Likewise, spouses of ALS/MND patients are significantly stressed and at higher risk for other diagnoses and suicide. Additionally, genetic risks shared among siblings and parents require more attention and support in clinics. She also underscored the importance of providing medical care at home to help families maintain quality of life while ensuring caregivers have needed support.

Dr. Melinda Kavanaugh and Dr. Priya Thomas addressed the social sciences gap in access to care. Dr. Kavanaugh discussed the often-overlooked role of social sciences in ALS/MND care and research, noting that healthcare systems often prioritize medical professionals, neglecting social science professionals despite the critical functions they provide by focusing on human society and relationships, directly influencing patient care through counseling, social work, and therapies. A balanced approach in healthcare funding and prioritization is needed, integrating social sciences to enhance quality of life for patients and their families. Lack of access and inclusion of social science professionals in ALS/MND care exacerbates stress and anxiety for patients and families. Effective ALS/MND care should include social science professionals to address social norms, culture, socioeconomic status, and caregiving roles.

Dr. Thomas offered some examples from India where ALS/MND care faces challenges due to the lack of universal healthcare and insurance coverage, leading to high out-of-pocket expenses. The sociocultural context in India requires tailored management strategies, with families playing a crucial role in caregiving. It is important to understand the socio-cultural backgrounds and socioeconomic status of patients in order to provide effective

care. An example of a successful initiative is a public-private partnership in India that integrates palliative care into routine neurology care at a tertiary care hospital. This approach ensures patients receive comprehensive care from diagnosis, considering their socioeconomic and cultural contexts. There is a significant need to support families in providing care, given the collectivist nature of Indian society where families often bear the brunt of caregiving responsibilities.

Dr. Tarun Dua described the approach of the World Health Organization (WHO) in tackling neurological disorders and advancing access to care globally, emphasizing the high burden on caregivers, the progressiveness of these conditions, and the lack of cures. Neurological conditions are a leading cause of disability and death globally, with 43% of the world population experiencing a neurological disorder. These disorders impose a significant burden, especially in low- and middle-income countries, where 80% of the burden resides. There is a stark disparity in the availability of neurological care professionals between high-income and low-income countries. High-income countries have 7 neurological professionals per 100,000 people, whereas low-income countries have only 1 per million. Even significant investments in workforce capacity will not drastically change this landscape. There is a lack of access to essential medicines, rehabilitation, and diagnostic services. For example, only one in ten people with dementia in low and middle-income countries receive a diagnosis, likely lower for ALS/MND.

To address these challenges, in May 2022, the World Health Assembly endorsed an action plan to address neurological conditions. The plan's vision is to promote and protect brain health, ensuring prevention, diagnosis, and treatment of neurological disorders while supporting the highest possible level of health and equal rights for affected individuals and caregivers. The plan includes seven guiding principles: gender equity, human rights, empowerment and involvement of affected individuals and families, intersectoral action, evidence-informed policy, integrated and multidisciplinary care, and people-centered primary healthcare. The action plan outlines five strategic objectives with specific actions for member states, WHO Secretariat, and international/national partners, accompanied by ten global targets. Objectives include prioritization and governance, diagnosis, treatment and care, primary healthcare enhancement, caregiver support, promotion and prevention, research innovation, and information systems. The WHO emphasizes the need for policy advocacy, guidelines, and tools to support countries in implementing the action plan. Collaboration and partnerships, particularly with affected individuals, are crucial for successful implementation.

Dr. Richard Bedlack discussed opportunities in leveraging telemedicine to help close the care gap for people living with ALS/MND. Telemedicine involves exchanging medical information between patients and clinicians in different locations using technology, such as phone or video conferencing. It has evolved significantly since its early mention in 1924, with current options allowing hospital-to-hospital or office-to-home interactions, and synchronous (real-time) or asynchronous (store-and-forward) communications. ALS/MND is a rare disease, and many patients live far from specialists. Evidence-based treatments for ALS/MND can significantly impact prognosis and quality of life, but many patients are unaware of these options due to the rarity of the disease and the expertise gap among general practitioners. Telemedicine helps bridge this gap, providing access to expert care and improving quality of life. Telemedicine can also decentralize research, increasing diversity and inclusion in clinical trials. Studies show that telemedicine can provide care of equal or better quality compared to in-person visits, with improved patient outcomes and cost savings. The goal is to ensure every ALS/MND patient worldwide has access to expert care, education about treatment options, and support to realize their hopes.

The pandemic drastically increased telemedicine usage due to travel restrictions and changes in insurance policies. Post-pandemic, some barriers have returned, but many providers continue to offer telemedicine services, supported by grants from patient advocacy groups. Telemedicine is now used by many ALS/MND patients and institutions, with some providers conducting virtual visits across multiple states and countries. New organizations focus on tele-ALS/MND education and medical care, circumventing legal barriers and expanding access. Patients can initiate telemedicine visits by contacting their doctor, who will provide instructions and necessary software. The process is user friendly and adaptable, even for those with limited technical skills. The future of tele-ALS/MND looks promising, with advancements in virtual pulmonary function tests, digital biomarkers, and multidisciplinary team consultations.

Key Takeaways and “calls to action” from the presentations during the plenary session included:

Telemedicine

- Patient advocacy groups to provide funds and advocacy efforts to overcome barriers for telehealth access to ALS/MND experts around the world.

Global Partnerships

- The World Health Organization to engage in partnerships and collaborate with stakeholders, especially people with lived experience, to implement the intersectoral Global Action Plan for neurological disorders.

Health Systems:

- Healthcare systems to invest in primary healthcare systems and integrate social science professionals like social workers, counselors, and occupational therapists for multidisciplinary care of ALS/MND patients and their families.
- Healthcare systems to establish multidisciplinary ALS/MND clinics or centers of excellence in major cities, focusing on patient and family care.
- Healthcare systems to provide training and resources for healthcare workers to enhance their capacity in caring for ALS/MND patients and supporting caregivers.
- Healthcare providers to involve families, including children, spouses, and caregivers, in open conversations and shared decision-making about ALS/MND care and treatment.
- Healthcare providers to ensure access to genetic counselling, mental health support, palliative care, and hospice care for ALS/MND patients and their families.
- Healthcare systems to ensure access to essential medicines, diagnostics, and assistive technologies for ALS/MND patients, considering the economic burden on families.

Data Collection:

- Researchers to conduct studies on the economic burden of ALS/MND on families and explore ways to provide comprehensive support systems for patients and caregivers.
- Researchers to invest in better data collection and information systems to understand the disparities in ALS/MND care across different regions and populations.

Policy:

- Policymakers to develop supportive policies, plans, and legislation that reflect neurological conditions and protect the rights of patients and caregivers.

Group Discussions

Roundtable participants participated in two group discussions to debrief on the presentations and provide specific insights about their geographies' access to care experiences and challenges. Each group was asked to consider the following questions:

- What are the capacity and infrastructure gaps in your region?
- Where can we collaborate to level access to care?
- Who are the key stakeholders to make change happen?
- What are the highest priority action steps the Alliance can take?
- What are the highest priority action steps associations can take?

Key Takeaways from the two small groups include:

- Access to care is limited in many parts of the world (e.g., Kenya and Vietnam), with long distances of travel and lack of transportation systems for people with ALS/MND to reach neurologists and other specialists for needed care. There is also a lack of awareness and sensitization among healthcare professionals about ALS/MND, and minimal government prioritization of ALS/MND as a healthcare issue. A focus is needed on expanding data collection efforts to better understand local needs and gaps in ALS/MND care infrastructure. There is also a lack of adequate mental health support for caregivers and families globally.
- There is a significant gap between available care resources and what patients and caregivers know about accessing them. Advocacy groups are seen as crucial in filling knowledge gaps and supporting patients and caregivers.
- Telemedicine is recognized as a crucial tool for improving access to ALS/MND care, especially in regions with few specialists. However, challenges such as technological infrastructure and regulatory barriers are noted.
 - Consider creating a program akin to "Doctors Without Borders," termed "ALS/MND Experts Without Borders," focusing on virtual tele-education to pair ALS/MND patients globally with expert clinicians who can guide them on treatment options and provide optimism.
 - There are logistical and practical issues to address in implementing this type of initiative, including the need for a centralized hub to coordinate efforts globally, and approaches to address limited technological access in low-income countries and language barriers. It will also be necessary to

- involve bureaucrats and NGOs to ensure sustainability and accessibility across diverse global contexts.
 - Participants expressed significant support for this idea, with suggestions to explore existing models and partnerships (like Summus Global) and seeking to incorporate AI for broader reach and efficiency.
 - Different countries and regions have experience with “hub and spoke” models for peer-to-peer networking to reduce isolation and expand connectivity across the ALS/MND global community.
- Participants support efforts to expand the ALS/MND Global Clinic Locator, a global database to help patients find ALS/MND professionals and services worldwide.
- Variability in access to care is complicated globally by different healthcare systems and structures for ensuring access to services and providing funding support. For example, voice banking technology and other assistive technologies are unevenly available around the world. Innovative solutions are needed, such as finding new ways to repurpose medical equipment and devices from countries with excess supply to those in need.
- Workplace accommodations and legislative support, such as the Americans with Disabilities Act in the U.S., are needed globally to enable ALS/MND patients to continue working and maintain financial stability.

Next Steps

The Alliance team will review all input received during the Roundtable and formulate priorities to support global efforts to enhance access to care for all people living with ALS/MND. Next steps for consideration by the Alliance include:

- Building a global landscape to better understand needs and gaps in ALS/MND care infrastructure
- Developing a communication plan to bridge the gap between available care resources and what patients and caregivers know about accessing them
- Scoping out a telemedicine project to advance the concept of "ALS/MND Experts without Borders"
- Expanding the ALS/MND Global Clinic Locator to include a comprehensive listing of ALS/MND multi-disciplinary care services
- Finding new ways to repurpose medical equipment and devices, and make them available to countries in need
- Advancing global workplace accommodations and policy change similar to the Americans with Disabilities Act in the U.S. to enable ALS/MND patients to continue working and maintain financial stability

Future Roundtable meetings will address other elements of the Fundamental Rights.