# Emergency Preparedness Roundtable Meeting Summary

May 2023

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#### **Executive Summary**

On May 17, 2023, a multi-stakeholder group, representing various communities within the International Alliance of ALS/MND Associations' network, gathered for a Roundtable focused on emergency preparedness for persons living with ALS/MND and the organizations that serve them around the world.

The Roundtable encompassed an opening plenary and two group discussions. The plenary session included a series of brief expert presentations designed to provide a foundation of knowledge about different types of emergencies, approaches to planning for them, recent experiences and the state of planning among the ALS/MND global community. During the group discussions, participants were invited to provide feedback on draft Alliance resources for persons living with ALS/MND and member organizations.

#### **Attendees**

Meeting participants included representatives from multiple global ALS/MND organizations, members of the Alliance's staff, the 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 Amylyx, Cytokinetics, MTPharma and Sanofi.

Plenary Session Attendees			
Last Name	First NAME	Country	Affiliation
Aquino	Irene	USA	Amylyx
Aquino	Pablo	Argentina	ALS Society of Argentina
Balas	Calaneet	USA	The ALS Association
Barry	Kim	Canada	ALS Society of Canada
Battista	Anthony	Canada	ALS Society of Canada
Beyerlin	Nancy	USA	MT Pharma
Blonk	Gorrit-Jan	Netherlands	The International Alliance of ALS/MND Associations
Chapman	Mark	UK	Motor Neurone Disease Association
Cummings	Cathy	Canada	The International Alliance of ALS/MND Associations
O´Connell	Dr. Colleen	Canada	Presenter - Physical Medicine and Rehabilitation
Sane	Dr. Hemangi	India	Asha Ek Hope Foundation
Dupont	Melissa	USA	Sanofi
Fagan	Gregory	USA	Sanofi
Feldman	Sara	USA	ALS Hope Foundation
Frey	Esther	Switzerland	Verein ALS Schweiz
Gswind	Laura	USA	Cytokinetiks
Gupta	Ajay	India	Asha Ek Hope Foundation
Kawaguchi	Yumiko	Japan	Sakura International
Kaya	Alper	Turkey	Presenter -ALS/MND Association Turkey
Mabe	Jessica	Colombia	The International Alliance of ALS/MND Associations
Maeder	Florence	Switzerland	Verein ALS Schweiz
Maginnis	Kimberley	USA	Presenter - Thre ALS Association
Maltby	Liana	Canada	The International Alliance of ALS/MND Associations
Moore	Tammy	Canada	ALS Society of Canada

Plenary Session Attendees			
Last Name	First NAME	Country	Affiliation
Mulcahy	Maxwell	USA	Apellis
Pearce	Laurie	Canada	Presenter - Disaster Management Educator
Pomerantz	Mary	USA	Cytokinetiks
Ruiz	Orlando	Colombia	Colombian ALS Association - ACELA
Santos	Marcela	Colombia	Colombian ALS Association - ACELA
Selig	Wendy	USA	WSCollaborative
Sigurdsson	Gudjon	Iceland	MND Iceland
Silverio	Conte	Italy	Associazione conSLAncio Onlus
Sung	Bugyeong	Korea	Korean ALS Association
Thakur	Neil	USA	The ALS Association
Toyer	Wendy	Canada	ALS Society of British Columbia
Van der Lit-van Veldhuizen	Angelique	Netherlands	ALS patiëntenvereniging
Van der Meijden	Conny	Netherlands	ALS patiëntenvereniging
Virgo	Bruce	Scotland	Member of the Alliance PCAC
Zou	Zhangyu	China	Beijing Oriental Rain ALS Care Center

Discussion Group 1 Attendees			
Last Name	First NAME	Country	Affiliation
Cummings	Cathy	Canada	The International Alliance of ALS/MND Associations
Barry	Kim	Canada	ALS Society of Canada
Blonk	Gorrit-Jan	Netherlands	The International Alliance of ALS/MND Associations
Chapman	Mark	UK	Motor Neurone Disease Association
Conte	Silverio	Italy	Associazione conSLAncio Onlus
O'Connell	Dr. Colleen	Canada	Presenter - Physical Medicine and Rehabilitation
Sane	Dr. Hemangi	India	Asha Ek Hope Foundation
Fagan	Gregory	USA	Sanofi
Kawaguchi	Yumiko	Japan	Sakura International
Kaya	Alper	Turkey	Presenter -ALS/MND Association Turkey
Mabe	Jessica	Colombia	The International Alliance of ALS/MND Associations
Maginnis	Kimberley	USA	Presenter - Thre ALS Association
Santos	Marcela	Colombia	Colombian ALS Association - ACELA
Selig	Wendy	USA	WSCollaborative
Sigurdsson	Gudjon	Iceland	MND Iceland
Thakur	Neil	USA	The ALS Association
Van der Lit-van Veldhuizen	Angelique	Netherlands	ALS patiëntenvereniging
Van der Meijden	Conny	Netherlands	ALS patiëntenvereniging
Virgo	Bruce	Scotland	Member of the Alliance PCAC
White	Jesse	Canada	The International Alliance of ALS/MND Associations
Zou	Zhangyu	China	Beijing Oriental Rain ALS Care Center

Discussion Group 2 Attendees			
Last Name	First NAME	Country	Affiliation
Cummings	Cathy	Canada	The International Alliance of ALS/MND Associations
O'Connell	Dr. Colleen	Canada	Presenter - Physical Medicine and Rehabilitation
Dupont	Melissa	USA	Sanofi
Kawaguchi	Yumiko	Japan	Sakura International
Mabe	Jessica	Colombia	The International Alliance of ALS/MND Associations
MacIsaac	Norm	Canada	Member of the Alliance PCAC
Maginnis	Kimberley	USA	Presenter - Thre ALS Association
Ocampo	Felipe	Colombia	Member of the Alliance PCAC
Pearce	Laurie	Canada	Presenter - Disaster Management Educator
Ruiz	Orlando	Colombia	Colombian ALS Association - ACELA
Selig	Wendy	USA	WSCollaborative
Toyer	Wendy	Canada	ALS Society of British Columbia
White	Jesse	Canada	The International Alliance of ALS/MND Associations
Zou	Zhangyu	China	Beijing Oriental Rain ALS Care Center

#### Agenda

Agenda Detail					
Plenary: Tuesday May 17: 7:00-8:30am ET (New York)					
<ul> <li>Contextual overview</li> </ul>	Cathy Cummings				
<ul> <li>Natural and human caused hazards</li> </ul>	Laurie Pearce, Ph. D.				
<ul> <li>International humanitarian disasters</li> </ul>	Dr. Colleen O'Connell				
<ul> <li>How the UN system responds to interest</li> </ul>	national disasters				
<ul> <li>Emergencia preparedness and respon</li> </ul>	se				
<ul> <li>Association / PALS perspective</li> </ul>	Dr. Alper Kaya				
<ul> <li>First 24 hours / First week</li> </ul>					
<ul> <li>Emergency expert</li> </ul>	Laurie Pearce, Ph. D.				
<ul> <li>Potential hazards and risks</li> </ul>					
<ul> <li>Supply chain &amp; infrastructure</li> </ul>					
<ul> <li>Business continuity</li> </ul>					
<ul> <li>Trauma of being involved in emergency events</li> </ul>					
<ul> <li>Association perspective</li> </ul>	The ALS Association				
<ul> <li>Questions</li> </ul>					
<ul> <li>Wrap up &amp; discussion group instructions</li> </ul>					

**Group Discussion** 

Virtual: Tuesday, May 17; Group 1: 9-10:30am ET: Group 2: 7-8:30pm ET

Debrief from Plenary

Facilitated Discussion:

#### PALS & CALS Toolkit:

- 1. What do you think the three (3) most important things are, for PALS & CALS to consider?
- 2. How do you suggest we package this information so that it's not overwhelming and is used?
- 3. How should we reach people and start the conversation with our community?

#### ALS/MND Association Emergency Preparedness Plan:

- 1. What experience have you had in implementing an emergency plan, and what worked for you.
- 2. What are the 3 most important things in an emergency preparedness plan.
- 3. What are the barriers to prepare an emergency preparedness plan?
- 4. How can the Alliance be helpful to get you to a proactive place?

Wrap up and next steps

The outcomes of the Emergency Preparedness Roundtable meeting are embedded in the document that follows.

#### Background

Alliance Executive Director Cathy Cummings provided the background and context for the Roundtable, noting the topic of emergency preparedness is timely and highly relevant to the global community given recent highly disruptive global and regional emergencies, including the COVID-19 pandemic, the earthquake in Turkey, hurricanes in parts of the US and conflict zones. She stressed the importance and relevance of the well-known scouting motto, "Always be prepared," especially in today's world with its frequent emergencies, including natural disasters, conflicts or wars, power outages or other unforeseen circumstances. In all cases, these are difficult situations for people living with ALS/MND and their families.

A recent Alliance survey of its member organizations found that more than three-fourths do not have a current emergency preparedness or business continuity plan. The goal of this Alliance Roundtable is to provide timely and actionable expert input to help member organizations and individuals with ALS/MND prepare to meet whatever type of emergency they may face.

#### **Expert Presentations**

During the plenary session, Roundtable participants received expert input to understand various types of emergencies and their impact, as well as global humanitarian activities to advance preparedness and ensure timely response. Additionally, the group heard a first-hand account of how the ALS/MND community in Turkey responded to and dealt with the impact of the disastrous earthquakes in that country. Finally, the ALS Association provided an organizational perspective based on its recent experiences in the US.

## Dr. Laurie Pierce, Royal Roads University & British Columbia Institute of Technology, North Vancouver, British Columbia

Dr. Pierce began the meeting by providing a brief overview of three types of hazards, or threats, including natural hazards, diseases/pandemics/pest infestations, and human caused. These events can occur any time and anywhere with varying opportunities for advance warning. Certain regions or geographies are more prone to some types of hazards than others (e.g., earthquakes, hurricanes, flooding, forest fires, famine, conflict, etc.). Generally, it is not possible to prevent the occurrence of a hazard, but it is possible to reduce their impact by preparing for them.

A key step for individuals, families and communities to take in preparation is to build a "hazard profile" by evaluating what types of hazards are more likely to occur in their area.



For example, people living along a coastline might be more focused on storms and flooding, while those living in a mountainous area might think more about fires or landslides. People who live in earthquake-prone regions would consider those impacts. In each case, the immediate aftermath of the hazard might vary. Guidance might be to evacuate or shelter in place. Power outages might be likely. It may be difficult to travel or reach necessary services and supplies. Thinking about what type of emergency might happen and how it could impact people living in the area is a necessary building block to developing an emergency preparedness plan.



#### **Important Things To Know**

- 1. Could it happen in my community?
- 2. Where would it happen?
- 3. Am I or my organization at risk? History + Change in Risk?
- 4. Is there a possible warning?
- 5. Who would tell me?
- 6. What would they tell me: Stay or evacuate?

Dr. Pierce also provided the group with information on managing hazards and disasters, ensuring its resilience from an organizational and business continuity perspective.



#### **Building Resilience**

- Builds on the capacity of an organization to anticipate, prepare, respond and adapt for the future
- Resilience is the ability of organizations and communities to mitigate hazards, contain the effects of disasters and carry out recovery activities in ways that minimize social disruption

It is important to determine the organization's critical business functions in terms of services it provides its members on a regular basis and during a disaster situation. Additionally, it is necessary to consider how the organization's staff and community volunteers will function and be supported, as they too are experiencing an emergency.



## What is Business Continuity Management?

- Business Continuity
- Emergency Management
- Crisis Communications
- Business Recovery



In preparing for a potential emergency, organizations need to think about four things:

- 1) Is it possible to eliminate the hazard?
- 2) How can we reduce the risk or the likelihood of that event taking place?
- 3) What can we do to reduce the consequences?
- 4) How can we share the cost or the pain of the event with others?

It is also important for organizations to help their individual constituents prepare for emergencies so that they are better equipped in the event of a disaster and to develop partnerships with other organizations and local disaster management agencies who have complementary capabilities so that all aspects of need can be managed in the event of an emergency. Organizational plans should also include evaluating what would need to be done in the short term and in the longer term if the aftermath of a disaster lasts beyond a few days.

Additionally, attention should be paid to ensuring robust communication capacity, within the organization, among partners, and with constituents. Finally, it is critical to regularly review organizational emergency plans, and to update them with learnings over time.



## Writing & Testing the Business Continuity & Crisis Communications Plan

- Use checklists keep it simple
- Review the plan with all key players
- Engage local disaster & emergency preparedness staff
- · Run a tabletop exercise
- Review the plan every year, after an event or when things change

#### Dr. Colleen O'Connell, Stan Cassidy Centre for Rehabilitation, New Brunswick, Canada

Dr. O'Connell reviewed the international perspective and approach to emergency preparedness disaster response, noting that global disasters are becoming a major contributor to humanitarian crisis and have been exacerbated by increased forced migration. A "humanitarian crisis" or "complex humanitarian crisis" is a situation with large and complex humanitarian needs requiring external assistance and resources. In most of these instances there is also a significant disruption in health systems.

#### **Emergencies - Coordination of Response**

An **emergency** is "a situation impacting the lives and well-being of a large number of people or a significant percentage of a population and requiring substantial multisectoral assistance"

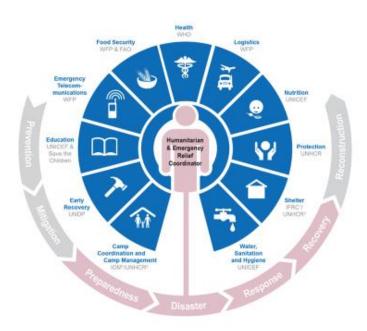
A **humanitarian crisis** is defined as any circumstance where humanitarian needs are sufficiently large and complex to require significant external assistance and resources, and where a multi-sectoral response is needed, with the engagement of a wide range of international humanitarian actors [major new emergency]

#### The "actors"

- United Nations (UN)
   Office for the Coordination of Humanitarian Affairs (OCHA), Inter-Agency Standing Committee (IASC)
- National Authorities/Government
- World Health Organization
   Pan American Health Organization (PAHO)

From a global perspective, there is a lot of headway that is has been made in terms of planning for emergency response. There is an initiative under the World Health Organization (WHO) called the "Emergency Medical Teams Initiative," which is establishing clear minimal standards to provide strategic, timely, predictable services, so that no matter where someone is in the world, they will receive quality service that meets a standard. The United Nations (UN), which leads coordination of international response to emergencies, has an emphasis on ensuring the protection and safety of persons with disabilities (including people affected by ALS/MND).

Provision of necessary services across many organizations occurs through a series of "clusters," including health, nutrition, protection, shelter, water, sanitation and hygiene.



In preparing for an emergency, communities and regions must evaluate their capacity to maintain essential services. However, it is common in the immediate aftermath of a disaster for specialized services and rehabilitation designed to support persons living with chronic disability to be cut back or de-prioritized.

An example of where these aspects resulted in tragic results occurred during Hurricane Katrina in the US. During this emergency, persons with mobility impairment were some of the most de-prioritized and unplanned for, and ended up with some of the highest death rates because they could not be evacuated.

While Dr. O'Connell emphasized the need to plan for these kinds of situations, ensuring that individuals and systems are focused on the needs of persons living with disability, she noted that many of the major global decision-making entities who lead disaster response and rehabilitation efforts are not as aware of these needs as they should be.

#### What is the solution?

 Raise awareness of decision makers of the importance of integrating rehabilitation into preparedness/early response

2. Raise awareness of rehabilitation professionals of importance of preparedness in their own services/roles



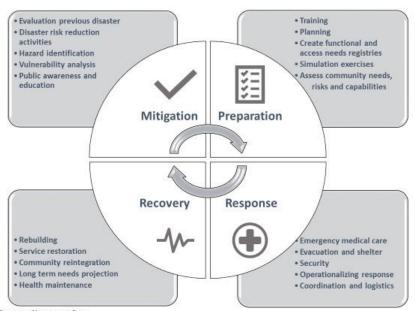


Figure 1. Comprehensive Emergency Management: Four phases of disaster cycle

She applauded the Alliance for leading efforts to help the global ALS/MND community advocate with decision-makers about the importance of thinking about the unique needs of vulnerable populations and prepare individuals, families and ALS/MMND associations to plan for emergencies.





#### Dr. Alper Kaya, Chairman, ALS/MND Association, Turkey

Dr. Kaya provided a first-hand account of the devastation and aftermath of recent earthquakes in Turkey, and how the ALS/MND Association worked to help people living with ALS/MND in affected regions. He shared multiple before and after images to convey the extent of the devastation to infrastructure and communities across the country. In describing the significance of power outages, transportation challenges and isolation caused by the earthquakes, he noted the importance of the first 24-48 hours after the event as a "race against time" to find and reach people living with ALS/MND who depend on power-driven technology to survive. Dr. Kaya and his colleagues partnered with the many organizations deployed to provide overall support and assistance and organized a team to meet the urgent needs of the approximately 550 ALS/MND patients affected by the earthquake disaster.

He shared several lessons learned from this experience, including the need for organizations serving people living with ALS/MND to have reliable records about who their constituents are, where they live and how to reach them. Emergency pagers can be life saving for immobile and abandoned patients, as can long-life batteries, back-up generators, and access to other independent power sources. Individuals should develop a plan, maintain fully charged batteries for their assistive devices, and keep a disaster kit and extra drinking water in their homes or cars.

#### Kim McGinnis, The ALS Association, United States

On behalf of the ALS Association, Kim McGinnis provided an overview of her organization's perspective and activities to plan for and respond to emergencies. She stressed the importance of being intentional and proactive, even when it may seem that a disaster is not likely to happen in your community. She described recent situations involving devastating hurricanes in the southeastern US, across five states, where about 3,000 people are living with ALS/MND. A key aspect of the Association's response was to coordinate with partners, including local fire and rescue personnel, to ensure that services could be provided to those in need.

People living with ALS/MND are encouraged to make sure their local first responders know them and are aware of their circumstances so that if disaster strikes, they are on the radar of the rescue teams' local staff. The ALS Association can mobilize its national staff, alongside its local staff, while deploying teams of volunteers who want to help.

#### **ALS** Considerations



Planning for every type of emergency/disaster is not possible



Implementing coordinated and collaborative processes to address the needs of our communities through local presence



Maintaining service continuity pre-event, during the event, and post-event



Utilizing Association-wide resources as a part of the response



Collaborating with designated formal responders

### "Help Teams"

## **Association Staff**Nationwide

## **Association Staff** Local

#### **Volunteers**

- Association business continuity planning
- Helping folks register as vulnerable adults e.g., local fire & rescue squads, local orgs.
- Direct phone calls to people/families
- Working with local organizations
- Federal Emergency Management Agency (FEMA) grants – helping with paperwork
- Website content, Scripting messages
- Virtual Home Modification Assessments
- Funding/grant opportunities

While each situation may be somewhat unique, the Association focuses on six areas within its emergency preparedness efforts.

#### **ALS** Six Critical Areas of Interest

#### **Local Staff:**

safety, resources, and roles

#### **ALS Community:**

people living with ALS and their families

#### **Operations:**

critical services, communications, capabilities

#### **Facilities:**

security, alternatives, equipment

#### Finances:

contingency budgets, grants

#### **Collaborations:**

opportunities Association-wide

In addition to mobilizing support, the Association has also established a disaster relief fund to provide financial support in the wake of an emergency. Through this program, families impacted by ALS/MND can receive up to \$2,500 US for their immediate/short-term safety and wellbeing.

#### Gregory Fagan, Sanofi

Providing a brief perspective from the pharmaceutical industry, Gregory Fagan underscored the importance of business continuity, which relies on an interconnected web of people process and stuff. Industry focuses on supply chains to ensure that manufacturing of vital medicines and technologies can continue through an emergency, and products can be distributed to those who need them. Companies work closely with their vendors to plan for potential disruptions in normal processes and ensure collaboration with local partners in affected areas. The key is to have a plan and ensure that it is continually being assessed and updated as needed.

#### **Group Discussions**

Roundtable participants participated in two small group discussions to debrief on the expert presentations and provide feedback on two draft emergency preparedness resources, a toolkit for persons living with ALS/MND and their caregivers (PALS & CALS) and a preparedness plan template for ALS/MND associations.

Meeting participants found the plenary session presentations to be highly informative and "eye opening" about the need to plan and be prepared at both the individual and organizational levels. It is important to "combat lethargy, skepticism and procrastination" in being proactive, making and maintaining these emergency plans.

Jessica Mabe and Cathy Cummings from the Alliance each provided each group with a brief overview of the draft resources, which were developed for the global ALS/MND community by adapting existing resources. Links to access these resources can be found in the appendix of this meeting summary.



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5.2. Evaluate performance vs ideal performance.....

#### Discussion questions for each group included:

#### PALS & CALS TOOLKIT

- 1.What do you think the three (3) most important things are, for PALS & CALS to consider?
- 2.How do you suggest we package this information so that it's not overwhelming and is used?
- 3. How should we reach people and start the conversation with our community?

#### ALS/MND ASSOCIATION EMERGENCY PREPAREDNESS PLAN

- 1. What experience have you had in implementing an emergency plan, and what worked for you.
- 2. What are the 3 most important things in an emergency preparedness plan.
- 3. What are the barriers to prepare an emergency preparedness plan?
- 4. How can the Alliance be helpful to get you to a proactive place?

## Emergency Preparedness Resource for Persons Living with ALS/MND: Group Discussions

- Most important things for PALS & CALS to consider when assessing one's own personal risk and making/updating preparedness plans include availability or/access to:
  - Electricity/Generator/Charged batteries
  - Water
  - Connections with local officials, a close relative (who knows the patient), care support companies
  - Communication capabilities
  - Local, regional, and country/federal resources
  - o Participate in an emergency registry for your community or region
  - o Ambu Bag
  - Emergency medication kits
  - Nutrition, water, tube feeding and other life-sustaining supplies
  - Breathing/ventilator support (BiPAP)
  - Mobility/transportation
  - o Accessible shelter
  - Back-up plans in case your first option is not available or accessible (e.g., alternate power source, alternate pharmacy, alternate caregiver, alternate medical professionals, etc.)
  - Plans for the appropriate care for your pet(s)
- Suggestions for packaging the information to be most useful included:
  - Keep it simple so it is not overwhelming.
  - Checklist or toolkit, online forms that can be printed for paper copies (needed if power is out).
  - Focus on the most important things. Provide suggested items that people can refine and customize (rather than a blank form they have to work on from scratch).
  - Medical emergency card. ("Important! My caregiver(s) and I are extremely knowledgeable about my condition, treatment needs and equipment. Please work with us. Having my knowledgeable caregiver(s) with me during my hospitalization is very important to me.")
  - o Encourage use of calendar reminders to review and update plans every six months.
  - Create an "SOS bracelet" with a QR code for medical and equipment needs information for people impacted by ALS/MND.
  - o Infographics and interactive videos in multiple languages.
  - Provide specific content for children.

- Suggestions for dissemination reaching people:
  - Leverage Alliance and member association websites
  - Regular newsletters (postal and email)
  - Social media (including YouTube videos)
  - Meetings/Webinars
  - Train local health departments
  - Work with care coordinators

## Emergency Preparedness Resource for ALS/MND Member Organizations: Group Discussions

- Most important things in an organizational emergency preparedness plan:
  - o Recognize that this can happen and it is necessary to prepare.
  - Create an "action team" to implement your plan:
    - Follow the advice of experts in the field.
    - No need to "re-create the wheel."
    - Training/Practice drills (tabletop exercises)
    - Knowledge of/accessibility to the plan details
    - Communication across the organization
    - Speed of activation
    - Promote planning tied to specific times of the year when certain natural hazard emergencies are more likely to occur (e.g., hurricane season, monsoons, drought, forest fires, etc.).
  - Build alliances:
    - Connect with international support organizations (e.g., the Red Cross, Humanity & Inclusion).
    - Connect with local response teams and personnel to ensure they have information about unique needs of people with ALS/MND and will appropriately triage their needs as a priority in the immediate aftermath of an emergency.
    - Engage with organizations that provide care personnel for people with ALS/MND to evaluate their plans and ensure complementarity.
  - Provide resources to your constituents:
    - Conduct regional and community meetings (e.g., a "town hall" format on this topic).
    - Provide sample plans for individuals and families to model their own plans.
    - Leverage organizational website/homepage.
    - Ensure information about your constituents is backed-up and available if there is no power.
    - Ensure your constituents are signed up to receive information from the organization (set up "phone trees" in advance).
    - Provide emergency contact information.
    - Establish an emergency fund.
  - Support your organizational staff as they are experiencing the disaster situation.
- Barriers to preparing an organizational emergency preparedness plan:
  - Lethargy/sceptics/procrastinators in an organization

- Lack of resources adequate to prepare/implement
- Culture and language barriers
- o Potential liability if the organization is providing direct support
- Privacy constraints

#### • Role of the Alliance:

- Disseminate expert content from this roundtable.
- Provide workable, basic templates to enable member associations to form their plans and provide advice to their community for developing personal plans (work on organizing and packaging the most important information first to keep it streamlined and make it manageable for constituents).
- o Facilitate discussion within the membership.
- Facilitate discussion and building of alliances with other organizations that have expertise in these areas (emergency preparedness and response).
- Develop a public/community facing campaign (e.g., launch an "ALS/MND Emergency Preparedness Month").

#### **Next Steps**

Detailed feedback from the conversations within each group session is being combined, resulting in refinement of the draft resources and a foundation for dissemination plans. Next steps include finalization of these resource documents and additional Alliance activities to engage members and the ALS/MND community in planning to ensure preparedness for emergency situations.

#### **Appendix**

#### **Emergency Preparedness Resource for Persons Living with ALS/MND**

The link listed below will provide you with access to static and fillable versions of all the forms, allowing for user preference on how they would like to approach compiling the information.

Link: Emergency Preparedness Toolkit for PALS and CALS

- 1. Where to start checklist for PALS and CALS
- 2. PALS and CALS medical emergency card
- 3. Emergency telephone list
- 4. PALS medical summary
- 5. PALS medicine chart
- 6. PALS and CALS personal support network
- 7. Emergency supplies checklist
- 8. PALS personal assessment
- 9. Disability related supplies and special equipment checklist

#### **Emergency Preparedness Resource for ALS/MND Member Organizations**

You can find the emergency preparedness template <u>here</u>, in the members area of the Alliance website. The document is fully customizable for the member association to complete based on the information they have and their capacity.