



## Alliance Meeting Agenda

November 28, 29 & 30, 2022

*\*All times are shown in Pacific Standard Time (PST)*

*\*\*Times subject to change*

| November 28   |   |                                     |
|---|---|-------------------------------------|
| <b>CEO Roundtable/Welcome reception (Invitation only)</b> |   |                                     |
| <b>12:00 – 1:00 PM</b>                                    | <b>LUNCH</b>  |                                     |
| <b>1:00 – 4:25 PM</b>                                     |   |                                     |
| <b>Welcome and Looking to the Future</b>                  |   |                                     |
| 1:00 – 2:30PM   | Welcome From Alliance chair   | Calaneet Balas                      |
|   | March of Faces  |                                     |
|   | Welcome from the program chair  | Gudjon Sigurdsson                   |
|   | Using technology to plan for the future   | Lori Banker-Horner<br>Maureen Clark |
|   | Assistive technology  | Team Gleason                        |
|   | Global Clinic Locator   | Maureen Clark                       |
| 2:30 – 3:00 PM  | <b>Coffee Break</b>   |                                     |
| <b>Research &amp; Science</b>                             |   |                                     |
| 3:00 – 4:15 PM  | Developing young carer education and support programs in South Africa                       | Melinda Kavanaugh                   |
|   | The ALS Association strategy to increase the number of clinical trials in the ALS ecosystem | Kuldip Dave                         |
|   | The registry matters: Strategies for successful engagement                                  | Patricia Stanco                     |
| <b>HOST DINNER /ALS ASSOCIATION</b>                       |   |                                     |



| November 29                       |   |                              |
|-----------------------------------|---|------------------------------|
| 8:00 – 9:00 AM                    |   |                              |
| <b>AGM MEETING</b>                |   |                              |
| 9:00 AM – 12:15 PM                |   |                              |
| <b>Advocacy</b>                   |   |                              |
| 9:00 – 10:30 AM                   | Welcome back  |                              |
|                                   | UK government investment in MND research - one year on.   | Sally Light                  |
|                                   | Laying the groundwork for regulatory approval   | Tammy Moore<br>Lauren Poplak |
|                                   | Securing funding from government entities for ALS Research                                      | Kathleen Sheehan             |
|                                   | ALS/MND fundamental rights survey 2021 Report from Turkey                                       | Alper Kaya                   |
| 10:30 – 10:50 AM                  | <b>Coffee Break</b>   |                              |
| <b>Organizational Development</b> |   |                              |
| 10:50 AM -12:15 PM                | Rebranding a much loved organisation to better deliver your message                             | Rachel Maitland              |
|                                   | Organisational development  | Evy Reviere                  |
|                                   | The public value contribution of the ALS Organisation Switzerland                               | Walter Brunner               |
|                                   | Integrating the perspective of people affected by MND/ALS in our organisation                   | Rachel Maitland              |
| 12:15 – 2:00 PM                   | <b>GROUP PHOTO LUNCH</b>  |                              |
| 2:00 PM – 5:00 PM                 |   |                              |
| <b>ADVISORY COUNCILS</b>          |   |                              |
| 2:00 – 3:15 PM                    | Welcome back  |                              |
|                                   | Q & A with the Alliance’s Scientific Advisory Council (SAC)                                     | SAC                          |
|                                   | ITAC update   | ITAC                         |
| 3:15 – 3:35 pm                    | <b>Coffee Break</b>   |                              |
| <b>Programming for PALS/CALS</b>  |   |                              |
| 3:35 – 5:00 PM                    | PCAC update   | PCAC                         |
|                                   | My ALS Decision Tool™ and information guides  | Lauren Webb                  |
|                                   | ALS community support assessment to improve online access to information and resources in Italy | Daisy Sproviero              |



|               |  |               |
|---------------|--|---------------|
|               | Guide runner - Scenery of a family living with public nursing services | Hitomi Hasebe |
| <b>DINNER</b> |  |               |

|  |   |                               |
|--|---|-------------------------------|
| <b>November 30</b>   |   |                               |
| <b>8:00 AM – 12:20 PM</b>                                    |   |                               |
| <b>Programming for PALS/CALS and Multi-Disciplinary Care</b> |   |                               |
| 8:00 – 10:00 AM  | Welcome back  |                               |
|  | Empowering ALS community ambassadors  | David Taylor<br>Lauren Poplak |
|  | The Hope Bridges program  | Mary Holt-Paolone             |
|  | Multi-disciplinary care – An organizational perspective   |                               |
|  | Looking forward to 2023   | ALS Schweiz                   |
| 10:00 – 10:20 AM   | <b>Coffee Break</b>   |                               |
| <b>ALS/MND CONNECT</b>                                       |   |                               |
| 10:20 AM – 12:20 PM  | ALS/MND Connect   |                               |
| <b>12:30 -1:45 PM</b>  | <b>LUNCHEON</b><br><b>HONOURING 30 YEARS</b><br><b>CELEBRATING PALS &amp; CALS</b><br><b>Keynote Speaker: Colleen O’Connell</b> |                               |