



## Allied Health Professionals Program

November 30, December 1 & 2, 2022

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

*\*\*Times subject to change*

| November 30   |   |                                 |
|---|---|---------------------------------|
| 10:20 AM – 12:20 PM                                   |   |                                 |
| 10:20 AM - 12:20 PM                                   | ALS/MND Connect   |                                 |
| 12:30 – 1:45 PM                                       |   |                                 |
| <b>LUNCHEON</b><br>Keynote speaker: Colleen O'Connell |   |                                 |
| 2:00 PM – 5:10 PM                                     |   |                                 |
| Welcome   |   |                                 |
| 2:00 – 3:20 PM  | Welcome & about the Alliance  | Calaneet Balas                  |
|   | Welcome from the program chairs   | Sara Feldman<br>Rachael Marsden |
|   | March of faces  |                                 |
|   | Multi-disciplinary care panel   |                                 |
| 3:20 – 3:40 PM  | <b>Coffee Break</b>   |                                 |
| Activities of daily living                            |   |                                 |
| 3:40 – 5:10 PM  | Welcome back  |                                 |
|   | One year later, an update on My ALS Decision Tool™ and information guides               | Anne Marie Doyle                |
|   | "Positive Tiredness": A Concept to challenge fatigue management for people with ALS/MND | Helen Carey                     |
|   | Using and creating educational resources for families                                   | David Meissner                  |
|   | The wheelchair alliance   | Nick Goldup                     |
| 6:00 – 7:00 PM  |   |                                 |
| <b>ALS/MND WALK</b>                                   |   |                                 |
| 8:00 PM   |   |                                 |
| <b>RECEPTION</b>                                      |   |                                 |



| December 1   |   |  |
|--|---|--|
| 8:00 AM – 12:40 PM   |   |  |
| Care Management  |   |  |
| 8:00 – 9:50 AM   | Welcome back  |  |
|  | Establishing a neuro-palliative care clinic in the hospital setting: lessons learnt for ALS care  | Gargi S Kumar  |
|  | ALS Canada support group model  | Kim Barry  |
|  | Breaking News   | Dr. Angela Genge<br>Melinda Kavanaugh<br>Colleen O’Connell<br>Cathy Cummings |
| 9:50 – 10:10 AM  | Coffee Break  |  |
| Mental health, psychosocial and emotional support models of care |   |  |
| 10:10 AM -12:20 PM   | Welcome back  |  |
|  | Developing a web resource on experiences of inherited MND for patients, families and healthcare professionals   | Jade Howard  |
|  | Making sense: An online meaning centred psychological intervention for individuals with MND   | Sandra De Moree  |
|  | Mitigating stressors through building systems of support for children and young adults impacted by ALS.   | Lily Cola  |
|  | E-Learning on palliative and end-of-life care in ALS for all caregivers accompanying ALS patients in Belgium  | Liesbet Casier   |
|  | My ALS/MND patient mentioned wanting to die, now what? A brief guide to conversations about death, dying, and suicide screening for non-mental health | Amber Johnstone  |
|  | Virtual networking and posters  |  |
| 12:20 – 1:55PM PM  | POSTER LUNCHEON   |  |
| 2:00 PM – 5:40 PM  |   |  |
| Multi-disciplinary care  |   |  |
| 2:00 – 3:50 PM   | Welcome back  |  |
|  | Building local mental health support through education and collaboration  | Melissa Enfinger   |



|  |   |                      |
|--|---|----------------------|
| 2:00 – 3:50 PM                                     | Eating with dignity: Exploring how eating can be improved for people with Amyotrophic Lateral Sclerosis   | Gudlaug Gisladóttir  |
|  | Neck weakness in MND/ALS: An investigation of the relationship between walking ability and neck weakness, and how this impact management strategies | Stephanie Zhao       |
|  | BowALS: Understanding changing bowel habit in amyotrophic lateral sclerosis   | Jan Clarke           |
|  | Let's Talk about Sex and ALS  | Joanna Nunez         |
| 3:50 – 4:10 pm                                     | <b>Coffee Break</b>   |                      |
| <b>Assistive technology / Improving technology</b> |   |                      |
| 4:10 – 6:00 PM                                     | Welcome back  |                      |
|  | What we learned about making videogames more enjoyable to play for people living with MND: insights from a scoping review                           | Ben O'Mara           |
|  | Guidelines for healthcare professionals working with individuals with complex communication needs   | Lisa Bruening        |
|  | Augmentative and alternative communication (ACC): the AISLA model for evaluating and providing devices in Italy.                                    | Massimiliano Filosto |
|  | DuoRhythmo: a collaborative accessible digital musical interface for PALS and CALS  | Ivanyl Balazs        |
|  | Voice Banking - what is the current status of the technology and where do we go from here to help ensure it meets the needs of people with MND/ALS? | Richard Cave         |
| <b>DINE AROUND</b>                                 |   |                      |

|                           |   |                    |
|---------------------------|---|--------------------|
| <b>December 2</b>         |   |                    |
| <b>8:00 AM – 12:00 PM</b> |   |                    |
| <b>Research</b>           |   |                    |
| 8:00 – 10:00 AM           | Welcome back  |                    |
|                           | Gendered meaning making of caregiving among spouses of persons with ALS: implications for care. | Manjusha Warriar G |



|   |   |                  |
|---|---|------------------|
|   | Strengthening the Paradigm of Science and Patient Collaboration   | Allison Bulat    |
|   | A qualitative evaluation of the revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R) by the patient community                     | Danielle Boyce   |
|   | Abstract, research staff satellite meeting  | Tommy Bunte      |
|   | Virtual networking and posters  |                  |
| 10:00 – 10:30 AM                        | <b>Coffee Break</b>   |                  |
| <b>Speech therapy and communication</b> |   |                  |
| 10:30 AM – 12:00 PM                     | Welcome back  |                  |
|   | Allied Health Professional Award  |                  |
|   | MND professionals' community of practice  | Jennifer Bedford |
|   | The ALS Association's rapid access communication kit distribution program   | Alisa Brownlee   |
|   | Your voice, your choice – Speech language pathologist navigation of the ever-evolving process of voice banking for people with Motor Neurone Disease. | Rachel Robinson  |
|   | Looking forward to 2023   | ALS Schweiz      |
| <b>PACKED LUNCH</b>                     |   |                  |