

Alliance Meeting

# Program Book

2022



INTERNATIONAL ALLIANCE  
OF ALS/MND ASSOCIATIONS



## Using technology to plan for the future

**Presenters:** Lori Banker-Horner & Maureen Clark

The ALS Association Certified Center Program instituted in 1989, was based on the strategic objective to design, implement and monitor a national standard of best-practice care in the management of ALS. There are currently 74 Certified Treatment Centers of Excellence and 20 Recognized Treatment Centers in the US. Increasing access to ALS specialty multidisciplinary care for persons living with ALS is essential. Research has shown multidisciplinary care increases length of life and quality of life. The Association is committed to ensuring the current centers continue to provide the highest standard of care while identifying new opportunities for multidisciplinary clinic development.

## Access, collaboration, and innovation

**Presenter:** Daniel Vance

When Steve Gleason formed the Team Gleason Foundation, he wanted to ensure that individuals had access to the technology and equipment that addressed their unique needs of living with ALS/MND. Over the past 10 years, Team Gleason has built partnerships with leaders in the tech and equipment industry with a goal of providing resources to the community. By interacting directly with individuals through our program services and collaborating with industry leaders, Team Gleason has centered itself as a hub for future innovation and advocacy.

## Global Clinic Locator

**Presenters:** Maureen Clark, Amanda Stanko & Pat Dolan

We will introduce The Global Clinic Locator to the audience as an interactive resource that will enable the ALS/MND community to locate search for clinics based on their location.



## **Developing young carer education and support programs in South Africa**

**Presenters:** Dr. Melinda Kavanaugh, Dr. Andre Mochan, Sheila Slabber & Professor Thobeka Nkomo

This session will provide a brief overview of YCare including young carers and ALS in SA, adapting the YCare program, and capacity building in health care around young carers and caregiving programming. We will also discuss sustainability and next steps with implementing YCare with the MND clinic, MND Association, Univ of Wits in Joburg and UWM.

## **ABRELA Update**

**Presenter:** Tatiana Mesquita e Silva

ASSOCIAÇÃO BRASILEIRA DE ESCLEROSE LATERAL AMIOTRÓFICA (ABRELA) provides us with an update on their activities and how they dealt with Covid-19.

## **Asha Ek Hope Foundation Update**

**Presenter:** Dr.Hemangi Sane

The association shares with us their survey of Covid vaccinations in ALS/MND patients in India.



## **The ALS Association strategy to increase the number of clinical trials in the ALS ecosystem**

**Presenter:** Kuldip Dave

**Co-Authors:** Paul Larkin, Keith Gary, Neil Thakur & Kuldip Dave

The ALS Association leads the way in research, care services, public education and public policy, giving help and hope to those facing the disease. The Association recently set an audacious but achievable goal to make ALS a livable disease by 2030, and will do whatever it takes to meet that goal. In particular, we identified three actions: 1) finding new treatments and cures, 2) optimizing current treatments and care, and 3) preventing or delaying harms associated with ALS. Here, we will describe the specific efforts we are making to increase the number of clinical trials in the ALS ecosystem.

## **The registry matters: Strategies for successful engagement**

**Presenter:** Patricia Stanco

**Co-Authors:** Patricia Stanco, MHS, Associate Director & Mission Engagement

The CDC (Centers for Disease Control and Prevention) National ALS Registry celebrates 10 years in operation this year. The Registry pulls statistics from existing databases and counts ALS cases to determine prevalence. It is also the only United States research program to invite people with ALS to answer risk factor questions, participate in a biorepository, and receive clinical trial alerts. Registry enrollment is crucial to the success of this research, which depends on large, representative samples of people with ALS to generate actionable findings. Nonprofit organizations play a vital role in educating the community about the Registry to increase enrollment.



## **UK government investment in MND research - one year on**

**Presenter:** Sally Light

To provide the Alliance community with a progress update on the £50m pledge from the UK government for MND translational research and to draw out learnings which may be useful for other organisations.

## **Laying the groundwork for regulatory approval**

**Presenters:** Tammy Moore & Lauren Poplak

Building a foundation of champions within government is critical to advocating for policy changes that will have a meaningful impact on people living with ALS today and in the future. That is why the ALS Society of Canada engages with government officials as a trusted source of information and a connection to the experiences and perspectives of Canadians affected by ALS. This approach has enabled ALS Canada to work directly with government on improving the mechanisms for patient input to ensure decisions about ALS therapies are made with the realities and needs of people with ALS at the forefront.



## **Securing funding from government entities for ALS Research**

**Presenter:** Kathleen Sheehan

The ALS Association's advocacy work focuses on educating and mobilizing members of Congress and the Administration in a nonpartisan way to achieve our mission of discovering new treatments and a cure for ALS, and serving, advocating for and empowering people living with ALS to live their lives to the fullest. To do this, government funding for ALS research must be expanded to provide new treatment options to cure and prevent ALS. Government research dollars need to be focused on discoveries that will improve the lives of people living with ALS today, while we search for ways to end ALS. The Association's advocacy team has and will continue this via a multi-pronged effort that includes direct lobbying, advocate engagement, and issue advocacy campaigns. Specifically, this means advocating for funding across multiple government agencies, direct work with government officials and rallying advocates to strategically engage with decision-makers.

## **ALS/MND fundamental rights survey 2021 Report from Turkey**

**Presenter:** Alper Kaya

**Co-Authors:** Hilmi Uysal

The International Alliance of ALS/MND Associations supports fundamental rights for people living with ALS/MND and their Caregivers. The survey was based on those ideal rights and respondents were asked to answer questions based on their experience in their countries and with regard specifically to their ALS/MND experience. Data collection began with a soft launch on Thursday, August 19th and then was rolled out fully on Thursday, August 26th. Respondents were invited directly and also arrived via social media. Those arriving via social media were screened via a CAPTCHA (Completely Automated Public Turing test to tell Computers and Humans Apart) interface. Data collection closed in the morning of Monday, September 27th.



## **Rebranding a much loved organisation to better deliver your message**

**Presenter:** Rachel Maitland

MND Scotland, and its brand, was well known to our warm audience. The cornflower logo was much loved but to a wider audience meant little. The organisation as a whole was moving on, entering a new chapter and yet the look and feel of the branding felt tired and stale and did not communicate our key message, one that is so important for people across the country to hear. So, we asked ourselves the challenging question: are we brave enough to change?

## **New offices of ALS Liga Belgium: finally home after a long odyssey**

**Presenter:** Evy Reviere

For non-profit organizations, finding suitable housing for its offices at an affordable price is not obvious. So it was for ALS Liga Belgium. For over two decades, we completed a real estate journey characterized by several forced relocations and changing rental market conditions, This odyssey finally came to an end on June 21 ALS Awareness Day the day we inaugurated our new offices located in Leuven, Belgium.

In this presentation we will provide an overview of the gathering of the necessary resources, the customized renovation of the building, the emphasis on accessible facilities for pALS, and the festive opening of our offices.



## The public value contribution of the ALS Organisation Switzerland

**Presenter:** Walter Brunner

Public value describes the value that an organization or activity contributes to society. The term was originally coined by Harvard professor Mark H. Moore who saw it as the equivalent of shareholder value in public management. Public value is supposed to provide managers with a notion of how entrepreneurial activity can contribute to the common good. Nowadays, public value is no longer limited to the public sector, but is used by all types of organization, including non-governmental organizations and private sector firms. Therefore, the public value researcher Timo Meynhardt from the University of St. Gallen and HHL Leipzig Graduate School of Management uses the term to generally raise the question about organizations' contribution to the common good. He believes that current management concepts, such as shareholder value, stakeholder value, customer value, sustainability or corporate social responsibility, should legitimize themselves in regard to their impact on the common good. In his (social-)psychological-based concept, public value emerges for individuals from the experiences made in social structures and relationships. Hence, it can be seen as a prerequisite and a resource for successful living. Walter Brunner, President of ALS Switzerland, is an official cooperation partner of Timo Meynhardt. The presentation uses Timo Meynhardt's unique public value theory to show how an ALS Non NFP organisation can generate public value for ALS patients, their families, stakeholders and society. The public value contribution of ALS Switzerland as a not-for-profit-Organisation is presented on the basis of five dimensions: Task performance: Is the organization doing a good job in its core business? Quality of life: Does the organization contribute to the quality of life? Cohesion: Does the organization contribute to cohesion? Morale: Does the organization behave decently? Legitimation to act: it is socio-politically legitimized? In terms of quality of life, the contribution also specially addresses the existential challenges posed by the life-limiting diagnosis. The presentation also shows the contribution that palliative care can make to the quality of life of ALS patients and their families.



## **Integrating the perspective of people affected by MND/ALS in our organisation**

**Presenter:** Rachel Maitland

**Co-Authors:** Rachel Maitland, Dr Jane Haley MBE & Gabrielle King

Integrating the perspective of people affected by MND/ALS in our organisation. It is of utmost importance that the perspective of people affected by MND/ALS is heard and integrated throughout the charities that represent them. Whether, or how well, this is achieved is likely to be very variable depending on the rigour, robustness and sensitivity of supporting processes.

## **ALS community support assessment to improve online access to information and resources in Italy**

**Presenter:** Daisy Sproviero

**Co-Authors:** Andrea Davide Zicchieri, Nicoletta De Rossi, Angela Desiderato, Silverio F. Conte, Marco Peviani, Monica Consonni, Silvia Pozzi, Tiziana Petrozziello, Daisy Sproviero, Fabiola De Marchi, Elena Grossini, Julio C. Ayala

Access to real time ALS scientific research news and support resources in non-English languages is often a challenging endeavour for people living with ALS (PALS), their families, and caregivers. To assess the ALS community needs to initiate a new series of virtual seminars promoted by a patient-led, multi-disciplinary Italian ALS association. To evaluate their interests in several ALS-related topics, PALS and family members were asked to fulfill a five-minute anonymous survey online. The survey was launched in May 2022 and included nine questions about: updates from clinical trials and scientific meetings, patient journey support, social supports, two open questions about scientific publications and other topics of interest. Despite the online survey has been open for one month, we have excellent feedback from the Italian community about our proposal to develop a new online seminar series on ALS. We will continue collecting surveys from additional participants in the next few months to build an online seminar series using a design-build approach



## **My ALS Decision Tool™ and information guides**

**Presenter:** Lauren Webb

**Co-Authors:** Lauren Webb & Ann Marie Doyle

My ALS Decision Tool™ explains ALS/MND treatment options in easy-to-understand language, breaking down the benefits and risks. The tool also includes questions to help people living with ALS/MND reflect on their needs and values. Based on each person's answers, the tool suggests resources and next steps. People living with ALS/MND can also save or print information from the tool to discuss with loved ones and their ALS/MND care team. My ALS Decision Tool™ currently has information about breathing and nutrition support devices. The Les Turner ALS Foundation is working on adding new topics to the tool like genetics.

## **Beyond ALS - Scenery of a family living with public nursing services**

**Presenters:** Hitomi Hasebe & Katsushi Tamaki

There are around 10,000 ALS patients in Japan. They are in the hospitals or staying at their home. Most of the people living with ALS need nursing services, but the allowed hours are not enough. We hope that every patient can live with families and caregivers using a public long term care insurance and others. ALS doesn't mean the end of life. If you are an ALS patient, you can choose another way of life even though you are in bed. We will show you a sample. Everyone can live with patience. Please find your best way of life. We really hope that all ALS patients live a happy life.



## **Empowering ALS community ambassadors**

**Presenters:** David Taylor & Lauren Poplak

There is an increasing desire from families affected by ALS to learn more about and advocate for the research landscape and how new therapies become available to Canadians. Recognizing an information gap, the ALS Society of Canada responded to this need, creating the Canadian ALS Learning Institute (CALI). Based on the NEALS-sponsored Clinical Research Learning Institute “and informed directly by people affected by ALS - the Learning Institute provides an opportunity for Canadians affected by ALS to learn more about the Canadian ALS landscape, clinical research, therapy development, and how new therapies become approved and accessible to Canadians.

## **The Hope Bridges program**

**Presenter:** Mary Holt-Paolone

Given the rapid progression of weakness, loss of independence and a multitude of increasing care needs, ALS/MND can be incredibly overwhelming to those with the disease and their families/care partners. This is magnified by the gaps in coverage and access to specialized emotional/psychological care, equipment needs and home support that can mitigate stress and improve quality of life. In order to fill these holes in support and care, the ALS Hope Foundation has developed the Hope Bridges Program.

## **Multi-disciplinary care – An organizational perspective**

**Presenters:** Sally Hughes, Dean Feener & Tammy Moore

Join us in this session to learn more about how UK MND Association and The ALS Association approach multi-disciplinary care within their organizations. We will hear from two different perspectives, their approach and barriers they encountered. This will be followed by a Q&A with the panel.

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## ALS/MND Connect

**Presenters:** Phil Green, Eugene Brandon, Dr. Caroline Ingre, Dr. Angela Genge & Dr. Colleen O'Connell

ALS/MND Connect is an open session which allows people living with ALS/MND and their caregivers to attend an afternoon of presentations by neurologists and researchers. This session is live-streamed on Facebook, so people with ALS/MND from around the world can attend and ask questions online.

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