

# 2019-2020 Annual Report



*United in the worldwide fight against ALS/MND*

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## Message from the Board Chair & Executive Director

This has been a year of disruption and change. The COVID-19 pandemic has upended everyone's lives around the world. While we have made great efforts to flatten the curve and do our part, what lies ahead remains unknown. That is what makes community and connection more important than ever.

Although the disease progression is different for every individual, and each of our member associations operates differently, there are some universal challenges that every organization in the ALS/MND space faces: How can we support people with ALS/MND in a meaningful way? How can we support their caregivers? How can we reduce the economic burden of the disease? How can we advocate for government and healthcare supports? How can we best manage the mental health challenges that come with the physical health challenges? Do we invest in research, care or both? Through connectivity in the Alliance, we are helping alleviate some of that stress.

The purpose of the Alliance is to achieve joint strategic goals by leveraging resources. Our Councils are prime examples of how we accomplish this valuable task. First, our Scientific Advisory Council, which now has 10 researchers representing diverse global communities and practices, acts as a centralized resource to review and provide global perspective on scientific and biomedical announcements, information and opportunities relating to ALS/MND. Second, our PALS & CALS Advisory Council guides the Alliance on the wide-ranging opinions and ideas of people with ALS/MND and caregivers to people with ALS/MND from across the globe. Third, our Innovation and Technology Council, which we established in March 2020, makes recommendations regarding technology and innovation strategies that will benefit those living and affected by ALS/MND globally. You heard from many of the dedicated members of these Councils at the Annual Alliance Meeting in December 2019. Their work is crucial to everything we do.



Calaneet Balas, Board Chair



Catherine Cummings, CAE, MBA



Your input as members is also vital, which is why we conducted a member survey in the spring of 2020. To ensure we continue to deliver value and fulfill our role as a global connector, we wanted to ensure we were aligned on the most important issues facing our member organizations and the ALS/MND community. We had 69 participants from a total of 28 countries from all continents except Antarctica.

From the results, we found that the most common challenges were around the lack of awareness and resources in government, professional circles and the public related to ALS/MND in each country. The consensus was that if there was more access to information, funding and other appropriate resources for both people living with ALS/MND and their caregivers, there would be fewer problems.

That is the focus of the Alliance, and it guides our strategies and operations. In 2019-2020, through the Annual Alliance Meeting, ALS/MND Connect and the Allied Professionals Forum, as well as the increased number of webinars we offered to help you navigate through the COVID-19 pandemic, we were there for you. We also worked to increase the profile of ALS/MND through the inaugural Global Walk to D'feet ALS/MND in December 2019 and the annual Global ALS/MND Awareness Day in June 2020, both of which were a resounding success.

Of course, we couldn't do the work we do without the generous sponsorship of Cytokinetics, FightMND, Stichting ALS, PayPal Giving Fund, IONIS, Orphazyme, Mitsubishi Tanabe Pharma, Biogen, AKO Foundation, FUNDELA and ALS Hope Foundation. We thank them for their ongoing commitment and support.

As you read through the 2019-2020 Annual Report, entitled *United in the worldwide fight against ALS/MND*, you will see how we are a gateway for all relevant stakeholders and a connector for all of us. As we continue through the pandemic, the Alliance will continue to work with all our communities and leverage these opportunities for change. With the collective commitment of our members to improve quality of care for people with ALS/MND worldwide, and educate and support professionals and volunteer groups in developing countries, we can create a brighter future.



Calaneet Balas, Board Chair



Catherine Cummings, CAE, MBA

“ With the collective commitment of our members to improve quality of care for people with ALS/MND worldwide, and educate and support professionals and volunteer groups in developing countries, we can create a brighter future. ”



## Who We Are

The International Alliance of ALS/MND Associations was founded in 1992 to provide an international community for individual ALS/MND Associations globally. We help members thrive by adding value to existing and future associations through curation and creation of information and by acting as a global gateway through which Alliance Members connect PALS & CALS to internal and external stakeholders

Our two main focuses are **Community** and **Capability** and we can do this as we build our **Capacity**.

## Our Vision

A world free of ALS/MND

## Our Strategic Priorities to 2022

- › **Build Community:** Build a global community. Identify, promote and support meaningful and timely in-person and virtual connections between members. Prioritize building membership in countries and regions that do not yet have membership representation. Be the gateway for relevant external stakeholders. Coordinate the global voice of PALS & CALS.
- › **Build Capability:** Build capability in member associations by soliciting feedback to ensure we focus on issues that deliver impactful value. Encourage member exchange of knowledge and facilitate discourse on issues. Deliver professional development that includes the Annual Alliance Meeting, but also provides member value throughout the year. Make our members stronger to advocate on behalf of individuals at the local level and provide a platform for global issues. Facilitate member peer-to-peer support. Be a gateway for external stakeholders to the network of domestic associations.
- › **Build Capacity:** To ensure we can move forward with these strategies it will be necessary to build internal capacity at the Alliance.



## Our 2019-2020 Board of Directors

The Board of Directors is responsible for the governance, compliance and strategic direction of the International Alliance.

### Chair:



Calaneet Balas,  
The ALS Association

### Vice-Chair:



Craig Stockton,  
MND Scotland

### Honorary Treasurer and Vice-Chair:



David Ali,  
MND Australia

### Directors:



Gudjon Sigurdsson,  
MND Association  
of Iceland



Evy Reviere,  
ALS Liga België



Kiki Qu,  
Taiwan Motor Neurone  
Disease Association



Andrea Pauls Backman,  
Les Turner ALS  
Foundation, USA



Tammy Moore,  
ALS Society of Canada



Nick Goldup,  
MND Association of  
England, Wales and  
Northern Ireland



Gorrit-Jan Blonk,  
ALS Netherlands



Pablo Aquino,  
ALS Association of  
Argentina

## Our Advisory Councils

### Scientific Advisory Council

The Scientific Advisory Council is a centralized resource to review and provide global perspective on scientific and biomedical announcements, information and opportunities relating to ALS/MND.

**Chair:** Dr. David Taylor, Canada  
**Board Liaison:** Gorrit-Jan Blonk,  
Netherlands  
Dr. Adriano Chiò, Italy  
Dr. Nicholas Cole, England  
Dr. Luis Barbeito, Uruguay

Dr. Qing Liu, China  
Dr. Jeannine Heckmann, South Africa  
Dr. Kuldip Dave, USA  
Dr. Gethin Thomas, Australia  
Dr. Caroline Ingre, Sweden  
Dr. Piera Pasinelli, Director, USA

### PALS & CALS Advisory Council

The PALS & CALS Advisory Council is charged with helping the Board of Directors consider and include in its work the wide-ranging opinions and ideas of people with ALS/MND and caregivers to people with ALS/MND from across the globe.

**Chair:** Sara Feldman, USA  
**Board Liaison:** Gudjon Sigurdsson,  
Iceland  
Dough Clough, USA  
Phil Green, USA  
Lee Millard, England

Marcela Santos, Colombia  
Carol Skinner, Canada  
Angélique van der Lit-van  
Veldhuizen, Netherlands  
Bruce Virgo, Scotland

### Innovation and Technology Council

The Innovation and Technology Council makes recommendations regarding technology and innovation strategies in line with the Alliance's strategic goals and principles that will benefit those living and affected by ALS/MND globally.

**Chair:** Nick Goldup, England,  
Wales and Northern Ireland  
**Board Liaison:** Tammy Moore,  
Canada  
Sara Feldman, USA  
Stuart Moss, UK

Jarnail, Chudge, UK  
Tom Oxley, Australia  
Dexter Ang, USA  
Mike Gardner, Canada  
Phil Green, USA

# We Are Not Alone in this Fight

## The 2019 International Meetings

The Annual Alliance Meeting, ALS/MND Connect and the Allied Professionals Forum were held in Perth, Australia, in December 2019, followed by the International Symposium on ALS/MND, hosted by MND Australia. These meetings showcase the spirit of collaboration and innovation in the ALS/MND research and clinical community, bringing together the brightest minds from the ALS/MND research and healthcare communities.

- › **The Annual Alliance Meeting** provides member associations the opportunity to meet and share advances in supporting people living with ALS/MND. It is a chance for representatives of ALS/MND associations from around the world to discuss organizational development and planning, patient care and funding, as well as the role and activities of the Alliance and its Board of Directors and Advisory Councils.

“Hearing what others are doing in different environments and with different challenges help me to understand alternative development pathways and introduction of technology. A good example is the use of meeting software to undertake face-to-face visits via screens. It is also fantastic to meet others and reinforce that we are not alone in this fight.”

– 2020 Member Survey Participant

“It is thanks to these meetings that we are in permanent contact with the main organizations globally and the most updated ALS information.”

– 2020 Member Survey Participant



- › **ALS/MND Connect** (formerly Ask the Expert) is a free session to connect people living with ALS/MND and their family and caregivers with leading international neurologists and researchers. This session is live streamed, so people from around the world can attend and ask questions online.
- › **The Allied Professionals Forum** is an educational and training forum for allied health professionals, such as physiotherapists, respiratory therapists, nutritionists, speech-language pathologists, social workers and more, who specialize in ALS/MND. This international forum offers healthcare professionals from around the world an opportunity to share ideas on good practice in the daily management of people with ALS/MND.

“ Highly beneficial to hear what others are doing and the environment they are doing it in, and identify opportunities to enhance and develop service delivery and support. ”

– 2020 Member Survey Participant

Thank you to our gracious hosts, MND Australia and MND Western Australia, whose warm hospitality, support and assistance made the 2019 meetings not only possible, but outstanding.

### By the Numbers

**290** attendees from **21** countries

**30+** presentations from associations and professionals from around the globe on topics ranging from innovation of care to supporting caregivers, using social media, promoting research and measuring outcomes

Members rate the Alliance Meeting and Allied Professionals Forum as **excellent value**, two of the top three offerings the Alliance provides

**30+** archived video and slide presentations from the meetings, with almost **1,000** views, available on the Alliance’s **2019 Meetings** page



## Letter from David Capelle, Travel Grant Recipient, December 2019

Dear Cathy [Cummings, Executive Director],

I would just like to express my thanks to the Alliance for having enabled me to join this meeting. I really did appreciate this opportunity to meet other people working in the fight against MND globally and certainly without the travel grant this would not have been possible for me.

As a delegate of MND Malaysia, I had the opportunity to join the Alliance meeting in Perth, Western Australia, last December. For me this was the first time participating in an Alliance meeting and it truly changed my perspective on how much can be achieved by joining forces. It is remarkable how the struggle against ALS/MND really goes beyond borders of culture and nationality.

I appreciated from the presentations about the Alliance's efforts in capacity- and capability-building that indeed national-level ALS/MND associations are not alone in their striving to advocate on behalf of patients with ALS/MND and achieve changes in the national healthcare and social support structures. While we may face somewhat differing challenges in different countries, there are also examples of how collaborations enabled by the Alliance have led to great projects being replicated in other ALS/MND associations, such as the Argentinian association drawing on the experiences of the Israeli association in organizing a fundraising run. The Alliance meeting is a great opportunity for everyone involved in the fight against ALS/MND to network and realize much more ambitious goals together.

My hope for the future is that until a cure for ALS/MND comes within reach, the work of the Alliance will continue to bring together all of us from the most diverse backgrounds.

With best regards,

David Capelle  
Kuala Lumpur, Malaysia



## Featured 2019 Presentation: The International Alliance Landscape Project

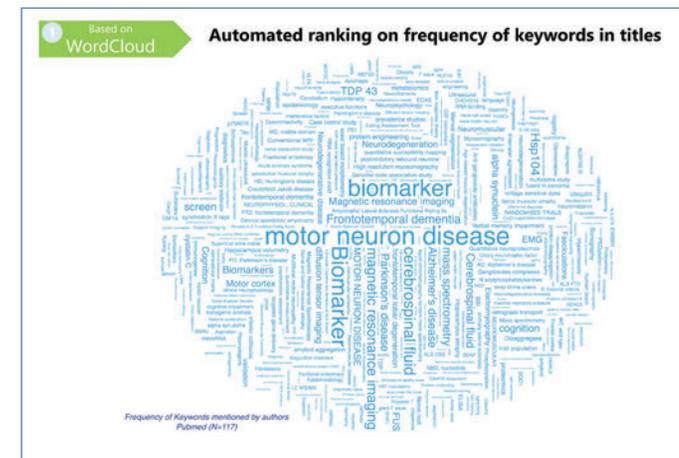
One of the strategic goals of the International Alliance of ALS/MND Associations is to promote and support scientific research for the cause, avoidance, cure and treatment of ALS/MND. In doing so, Alliance member will benefit from improved alignment and commitment on the focus areas for allocation of funds, and an improved decision-making process for new funding requests.

One exciting project to help us further this goal last year was the International Alliance Landscape Project. The genesis of this project was in the Netherlands, but the enthusiasm and support was worldwide. The Steering Committee included representatives from North America, South America, Asia-Pacific and Europe.

The objectives of this project were to create insight on current ALS/MND research activities to map who is doing what and where, and to create an overview of trends in academic focus areas. PubMed was used as a base for this analysis, and the largest category by far was the Pathogenic Understanding of ALS/MND (33%)—this is in line with expert expectations and earlier surveys because much of the research is still focused on cause of the disease. Runners-up included Therapeutic Targeting (laboratory) (18%) and Clinical Understanding (10%). And while most articles have a clear singular focus, the largest correlation with secondary focus involved Genetics & Pathogenic Understanding, Clinical Trials & Clinical Management, Biomarkers & Clinical Understanding, and Therapeutic Targeting & Pathogenic Understanding.

The Landscape Project has been instructive in many ways, not least of which is that we have a current snapshot at this point in time of what research is being done, by whom and in what volume. Other learnings from the project centre around what possibilities for the future could hold with a robust and iterative knowledge management strategy that is a living landscape used in decision making, collaboration and knowledge acceleration.

Knowledge management is the process of creating, sharing, using and managing the knowledge and information of an organization. It is a multidisciplinary approach to achieving organizational objectives by making the best use of knowledge, and the Alliance is well poised to be able to do this on behalf of our membership and the ALS/MND communities we all serve. Knowledge is an intangible asset but knowledge management programs can yield impressive benefits to individuals and organizations if they are purposeful, concrete and action oriented.



# It Takes a Global Effort

## Global Walk to D'feet ALS/MND

The number of different challenges people do to raise both money and awareness for ALS/MND is truly amazing. Kilt walks, city swims, pulling planes, marathons, trekking the great wall of China and various other adventures are happening almost every weekend. While these challenges are often community based, this year we held the first-ever Global Walk to D'feet ALS/MND on December 4, organized by MND Australia.

People affected by ALS/MND, scientists and delegates from around the world made their way along a 5-km course that followed the route of Perth's picturesque Swan River. There was an amazing turnout of around 400 people, each wearing their country's respective ALS/MND association or institution t-shirt.

Some of the various t-shirts worn during the event were donated and will be used to create a quilt. Proceeds attained from the quilt will be used to support the ALS/MND Patient Fellows Symposium Program.



“ It was inspiring to see so many people from across the globe coming together for the common purpose of raising awareness about ALS/MND. Of course, the conversations from the research sessions continued into the walk and I discussed at least two potential new research ideas and collaborations as we went along. ”

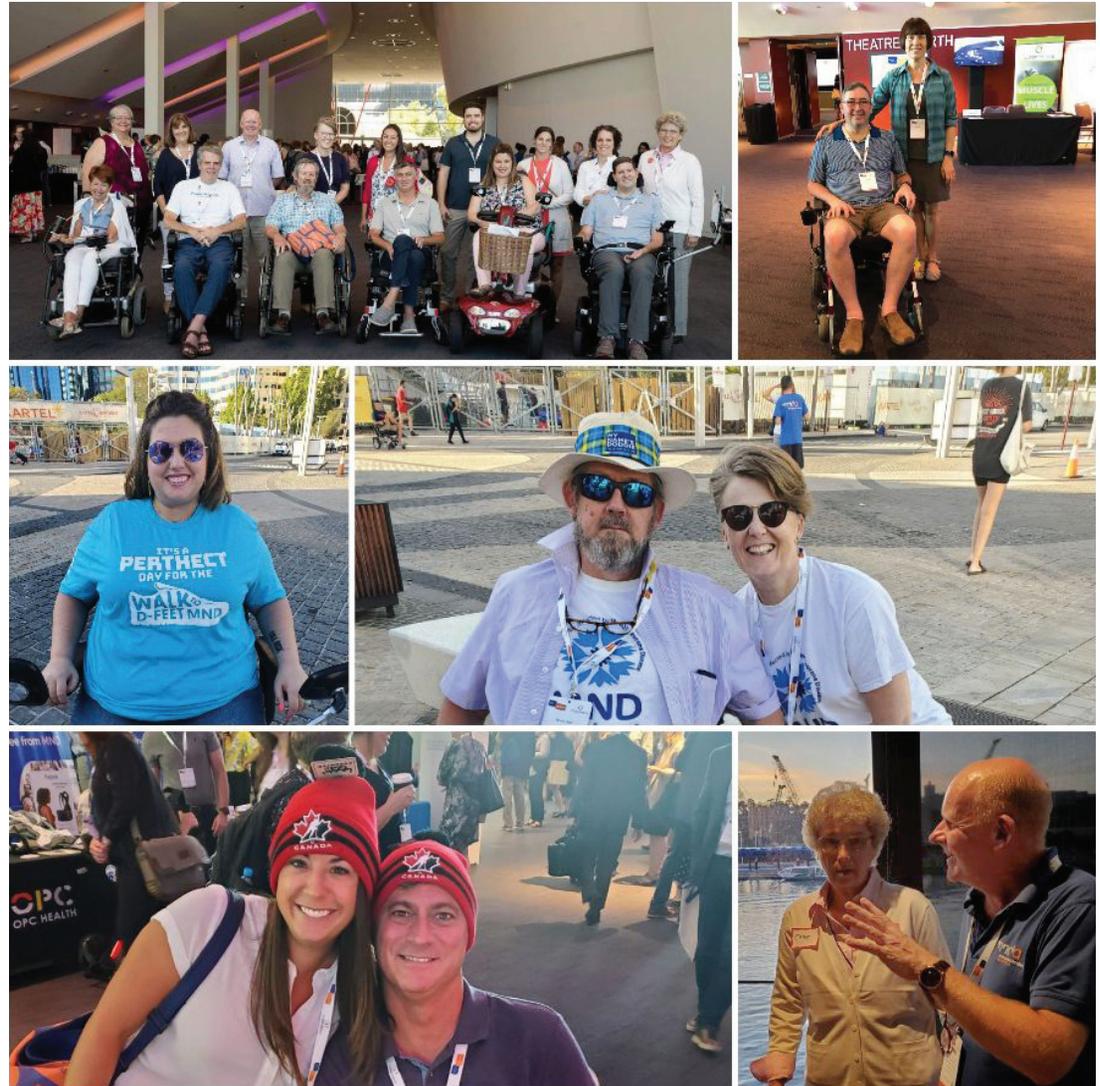
– Dr. Brian Dickie, Director  
of Research, MND Association of  
England, Wales and Northern Ireland



## Patient Fellows Symposium Program

The ALS/MND Patient Fellows Symposium Program helps people with ALS/MND to participate in the international meetings on ALS/MND. It was created out of a collective desire to further the relationship between ALS/MND patients and researchers; increase dissemination of research information in the tones and voices of patients; and include more people with ALS/MND in research conversations leading to greater inclusion of their thoughts, opinions and ideas in research decisions, trial designs, etc.

The 2019 Patient Fellows (top two photos at right) were supported by the ALS Therapy Development Institute (US); MND Association of Iceland; MND Association of England, Wales and Northern Ireland; and the International Alliance of ALS/MND Associations. A special thank you to Cathy Collette and Gudjon Sigurdsson for championing this program.



## Global ALS/MND Awareness Day

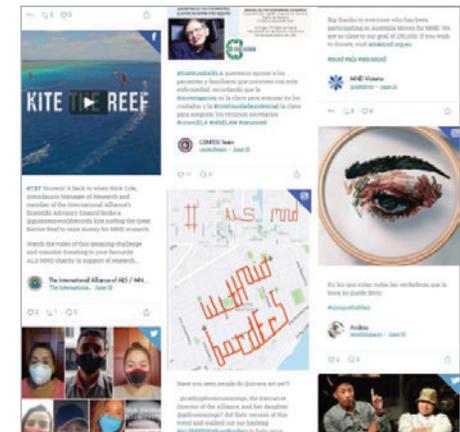
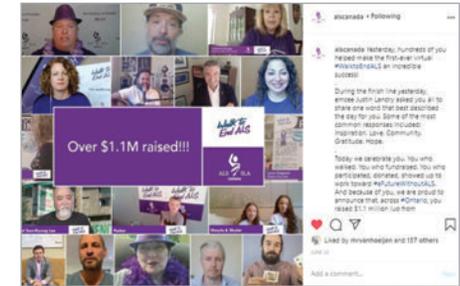


Thank you to everyone who made this year's Global ALS/MND Awareness Day a truly remarkable experience. Even though everything was virtual, the international ALS/MND community rallied together and made a real impact! The campaign ran from May 8 until the end of June, peaking on June 21—Global ALS/MND Awareness Day—with engagement from thousands of individuals, countries, clinicians, researchers, industry and, most importantly, the more than 200,000 people living with ALS/MND and their caregivers.

Thanks to all the work that each of you do, June 21 demonstrated that we are united in the worldwide fight against ALS/MND. You can still see all the posts from Alliance members around the world using the hashtag **#ALSMNDWithoutBorders**.

“ I am extremely hopeful about finding a cure for ALS/MND. The international collaborative efforts mean that our knowledge and understanding are progressing faster than ever before. On top of this, technology is advancing at an incredible rate and we are already seeing overwhelming developments, particularly in the field of gene therapy. Given the complexity of ALS/MND, the fight against it really requires a collaborative effort and I am inspired by the combined efforts across the world from patients and carers through to clinicians, researchers and charities. I am honoured to work alongside so many people that all share the common goal of curing ALS/MND. ”

– Tobias Moll, Postdoctoral Research Associate, Sheffield Institute for Translational Neuroscience



## The Personal Impact

On the eve of Global ALS/MND Awareness Day, one of the incredible volunteers for MND Victoria, Joseph, completed his mammoth goal of walking 2,100 km in 50 days, which represents 1 km for every person living with ALS/MND in Australia. Joe's passion for supporting people living with ALS/MND comes after losing his wife, Corinne, to the disease.

At 72 years old, he walked an average of a marathon a day and raised A\$29,192. The support Joe has from his family, friends and many colleagues is a true testament to the type of person he is.

## The Importance of Thank You

Seven years ago, one of the MND Association of Iceland's dedicated volunteers, Sandra, ran the Reykjavik Marathon for MND Iceland. One of the things she still remembers is a small note from Gudjon Sigurdsson, President of MND Iceland: "Thank you for running for those not able to." She still runs for the Association.

We can all use Global ALS/MND Awareness Day to generate awareness and recognize all of our supporters for their dedication and outstanding contributions.

## The Power of Connection

Due to COVID-19, the Colombian Association of ALS/MND cancelled its annual walk for ALS/MND. However, that did not stop them from spreading the message. They shifted their focus to social media, running several successful campaigns that drove awareness, support and donations in Colombia and worldwide.

- › **#OjosQueHablan #EyesThatSpeak** involved people outside of the ALS/MND community taking photos of themselves with masks on.
- › **#ConocELA** focused on sharing facts about the disease.
- › **#VivELA** shared stories from ALS/MND patients and their families of what it is like to live with ALS/MND.
- › **#LuzPorLaELA** saw the Colombian ALS/MND community send photos of themselves and their families wearing green, as well as having several buildings and monuments lit up in green to honour patients and their families.



## 2019 Award Winners

We are proud of all our members, and every year, we recognize certain individuals and groups among them who have demonstrated excellence in the ALS/MND community.

### Humanitarian Award



The recipient of the 2019 Humanitarian Award is Dario Ryba. Dario's father was diagnosed with ALS/MND in 2011. That same year, he founded the first and only organization for people affected by ALS/MND in Argentina. Dario has designed training programs for

caregivers, and authored self-help guides for people living with ALS/MND. His work has seen him travel to research centres and hospitals in different countries to learn and share information in relation to the research and treatments available to those living with ALS/MND.

Dario is the current President of UNELA (Union of Latin American ALS/MND Associations), which was established in 2018. In 2015, Dario was recognized in Argentina for his humanitarian efforts.

### Allied Health Professional Award



The recipient of the 2019 Allied Health Professional Award is Rachael Marsden. In her professional life, Rachel provides a point-of-contact service for patients between clinic visits, and facilitates the communication of information between all those locally involved in an individual patient's care. She has contributed to numerous publications as well as given numerous presentations and educational seminars on the care of

individuals with ALS/MND. A small sampling of her publications include co-author of "Motor Neuron Disease," as part of the Facts Series, published in 2008; and co-author of the Oxford Care Manual, *Motor Neuron Disease: A Practical Manual*, published in 2010.

In June 2019, she and her riding companion attempted to set a world record as the fastest women to circumnavigate the globe on a tandem bicycle. They raised a massive £37,000 for the MND Association of England, Wales and Northern Ireland, and Oxfam; set a new world record, beating the previous men's record by more than 17 days; and were recognized in the Top 100 Women in Cycling 2020.



# ALS/MND Doesn't Stop—Neither Can We

## COVID-19 Pandemic Response

Our work this year was overshadowed by the global COVID-19 pandemic and how it impacted people living with ALS/MND and their caregivers. As we navigated unfamiliar waters, we were reminded of how connected we all are and how important our International Alliance is. Never has a global gateway been more important than during these unprecedented times.

As we dealt with our own fears and uncertainties, we called on our resilience kept moving forward because we all work in a world where ALS/MND doesn't stop, so neither can we. One of the keys to being resilient is working with others because no individual has all the answers. It also helps to view the situation as an opportunity for change.

The Alliance seized that opportunity and truly demonstrated value in a tangible way to all our members. We exist to provide community, education and advocacy, and we have delivered on all three since the pandemic began.

- › **Member-only resources:** We acted quickly to update our website with COVID-19 resources for our members. For instance, we uploaded an FAQ document on COVID-19 and our ALS community, precautions that caregivers need to take now to keep themselves and the people they care for safe, and a webinar on virtual fundraising.
- › **Public resources:** We gathered resources from our members to help with public awareness and posted them to the website with acknowledgement. This also enabled us to offer resources in a variety of languages.
- › **Member roundtables:** We held four member roundtables (and will be continuing these in the future) to exchange ideas about trends that are emerging, opportunities on the horizon and how our peers are dealing with the difficult situations we are all facing right now. We had 40+ participants from every part of the world and sent a summary of the topics that emerged so those who were unable to join also benefit from the knowledge gained.

“ Fabulous to see the growth in Alliance offerings and increased member engagement over the last year or so. Congratulations on the response to COVID-19 and for bringing the community together at this difficult time. ”

– 2020 Member Survey Participant

“ I think we learned from COVID that we can bring associates even closer together through online platforms throughout the year. ”

– 2020 Member Survey Participant

“ I thank the Alliance for caring about improving and continuing to support ALS patients and their families. ”

– 2020 Member Survey Participant



- › **Webinars:** We hosted webinars so that PALS & CALS can hear from leading experts on research, clinical trials and care. Thank you to ALSA for providing the technology through GoToWebinar so we could have over 100 people participate live each time and record it for others to see afterwards. The topics included:
  - › COVID-19: Impact on Research and Clinical Trials Globally and Risk for People with ALS/MND
  - › COVID-19: Impact on Care Globally
  - › COVID-19 Roundtable: Impact on PALS & CALS
  - › COVID-19: Impact on Care (update)
  - › COVID-19: Emerging from the Pandemic
  - › Scientific Advisory Council Update and Q&A for Global ALS/MND Awareness Day

We will continue to host webinars so all our members can benefit from understanding the impact of the virus locally and globally, as ALS /MND truly is a disease that knows no borders.

- › **Advocacy letter:** A letter was developed under Calaneet Balas's signature to help those countries that were struggling to get ALS/MND recognized as a vulnerable disease. This letter was communicated to 36 CEOs of national associations and the feedback was very positive that it was helpful. It has been translated into many languages, and used with those respective governments and posted on websites in various countries.

Through all these initiatives, we have heard from members that they feel the pandemic has provided opportunities for change that will allow the ALS/MND community to not only bounce back, but bounce forward. We can leverage our learnings from this crisis to improve the world for PALS & CALS, including:

- › shortening pathways to policy and regulatory change;
- › improving access to clinicians and allied health professionals through telemedicine, where possible;
- › increasing the use of technology for support, which provides more accessibility to those who cannot travel to in-person support groups; and
- › improving pathways to empathy for those who now know what it is like to be isolated and physically distanced, similar to what people living with ALS/MND go through every day.

To face an uncertain future alone is daunting, but together we can feel supported and face it with strength. We remain united in the worldwide fight against ALS/MND!

“ I was new to [the webinars] and only attended one live, the others by recording. The concept I think works well and availability of later access a bonus. ”

– 2020 Member Survey Participant

“ Great work by the Alliance to support members and reduce wheel reinvention at this difficult time. ”

– Sally Light, CEO, MND Association of England, Wales and Northern Ireland

“ Now is the time to show solidarity with the ALS/MND International Alliance. ”

– 2020 Member Survey Participant





INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

## Excerpt from the Advocacy Letter

26 March 2020

The International Alliance of ALS/MND Associations would like to ensure that people with Amyotrophic Lateral Sclerosis or Motor Neurone Disease (ALS/MND) have been included in any governmental list or programs for extremely vulnerable persons in their guidance on shielding and protecting vulnerable persons from COVID-19.

....

By any name, ALS/MND is characterised by progressive degeneration of the motor nerve cells in the brain and spinal cord. The motor cells (neurones) control the muscles that enable us to move around, speak, breathe and swallow. With nerves failing to activate them, muscles gradually weaken and shrink. Progress is generally rapid, with an average life expectancy of between 2 and 5 years from the onset of symptoms. People living with ALS/MND often have a harder time with breathing and lung function, and therefore are at risk for COVID-19, regardless of age.

According to the World Health Organization, "people with pre-existing medical conditions appear to be more vulnerable to becoming severely ill with the virus." We believe that this pandemic has important implications for people with ALS/MND and we are calling on governments worldwide to define people with ALS/MND as being extremely vulnerable as a matter of urgency.

Sincerely,



Calaneet Balas, Chair  
International Alliance of ALS/MND Associations

