# Table of Contents

**Message from the Chair & Executive Director** ................................................................. 3

**Who We Are** ...................................................................................................................... 4-6
  - Our Vision ............................................................................................................................... 4
  - Our Strategic Priorities to 2022 ......................................................................................... 4
  - 2021-2022 Board of Directors .......................................................................................... 5
  - Advisory Councils ............................................................................................................... 6

**Bringing Our Global Community Together** ................................................................. 7-12
  - The 2021 International Meetings ....................................................................................... 7-9
  - The 2021 Award Winners .................................................................................................. 10-12

**Speaking Up for Our Rights** ....................................................................................... 13-15
  - Advocacy & Support ........................................................................................................ 13-14
  - Global ALS/MND Awareness Day .................................................................................... 15

**Setting the Path for a Brighter Future** ....................................................................... 16-20
  - Member Research ............................................................................................................ 16-18
  - Ongoing Education ........................................................................................................... 19-20
When the International Alliance of ALS/MND Associations was founded in 1992, the resources available to people living with ALS/MND and their health professionals and caregivers were scarce and hard to find. We stepped in to help fill that gap, to be a gateway and connector for all of us. Now, 30 years later, our purpose remains the same but our membership has grown to span 33 countries and 7 continents.

One of the key ways we enable collaboration among this large and diverse group is through our International Meetings. This is where our entire ALS/MND community can come together to share ideas, discuss care strategies and learn from experts throughout the world. There is nothing else like it. We all leave with a renewed sense of purpose, inspired by new ideas and driven by a feeling of urgency, as we know that for those living with ALS/MND time is all too precious and short.

An important topic presented at the International Meetings, as well as at other forums and events throughout the year, were the results of our survey on the Fundamental Rights of People Living with ALS/MND and of Caregivers of People Living with ALS/MND. These rights, first clarified over 20 years ago, drive all of the work the Alliance does because they are critical to supporting people living with the disease and those who care for them.

Unfortunately, the findings made it abundantly clear that people living with ALS/MND still do not have their fundamental rights respected at a global level and their caregivers are not well supported. How can we make it clear that everyone living with ALS/MND has the right to the highest quality of life, the highest quality treatment and the highest quality of care? How can we ensure that caregiver burden is recognised? These are the burning questions we are now working on with our member organizations.

This atmosphere of support and collaboration was the inspiration for the design of our 2022 Global ALS/MND Awareness Day campaign and this Annual Report. Titled “Neighbourhood,” the irregular shapes give the impression of an abstract map, providing a visual representation of the communities our member associations are working within, while the different colours and shapes highlight the many perspectives that form the ALS/MND community. Each shape works together to create a whole picture, and no matter the size, each offers an equal and important contribution to the whole.

Now more than ever, we are grateful for this widespread but interconnected community, made up of people living with ALS/MND and their caregivers, advocacy organizations, researchers, allied health professionals, scientists, and industry partners. Thank you for your support, and thank you for sharing our collective vision of a world free of ALS/MND.
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 and 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. Prioritise 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 and 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.
# 2021-2022 Board of Directors

<table>
<thead>
<tr>
<th>Chair</th>
<th>Vice-Chair &amp; Honorary Treasurer</th>
<th>Directors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calaneet Balas, The ALS Association</td>
<td>David Ali, MND Australia</td>
<td>Pablo Aquino, ALS Association of Argentina</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Andrea Pauls Backman, Les Turner ALS Foundation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nick Goldup, MND Association of England, Wales and Northern Ireland</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lung Kuo, Taiwan MND Association</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Evy Reviers, ALS Liga België</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Marcela Santos, ALS Association of Colombia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gudjon Sigurdsson, MND Association of Iceland</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hilmi Uysal, ALS MNH Derneği</td>
</tr>
</tbody>
</table>
Advisory Councils

Scientific Advisory Council
The Scientific Advisory Council is a centralised 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: Andrea Pauls Backman, USA
Dr. Adriano Chiò, Italy
Dr. Nicholas Cole, England
Dr. Kuldeep Dave, USA
Dr. Jeannine Heckmann, South Africa
Dr. Caroline Ingre, Sweden
Dr. Qing Liu, China
Dr. Piera Pasinelli, Director, USA
Dr. Gethin Thomas, Australia

PALS & CALS Advisory Council
The PALS & CALS Advisory Council helps 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
Phil Green, USA
Dr. Alper Kaya, Turkey
Albert Koo Tee Yih, Malaysia
Norman Maclsaac, Canada
Lee Millard, England
Dr. Felipe Ocampo, USA
Angélique van der Lit-van Veldhuizen, Netherlands
Bruce Virgo, Scotland

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

Chair: Blair Casey, USA
Board Liaison: Nick Goldup, UK
Richard Cave, UK
Jarnail Chudge, UK
John Costello, USA
Sara Feldman, USA
Mike Gardner, Canada
Phil Green, USA
Tammy Moore, Canada
Stuart Moss, UK
Bringing Our Global Community Together

The 2021 International Meetings

A primary role of the International Alliance is to be a knowledge broker, to benchmark and to break down silos. If someone has a good idea in technology that supports easier communication, we would like to see that available worldwide. If caregivers are supported through insurance or government funding in one jurisdiction, we would like to see that in all so that ALS/MND does not become a financial burden as well as a physical and mental one.

One of our most effective ways of accomplishing this information sharing is through our international meetings. In 2021, all the meetings were held virtually, with translation services available for the entirety of the conference, enabling our highest participation numbers to date.

"The reason I value the Allied Professionals Forum so highly is because it recharges my batteries for another year. I always leave with so many new ideas spinning in my head. It makes me focus on how I can improve the lives of people living with ALS/MND whom we care for."

"Grazie a tutti! Thank you to everyone! I truly enjoyed this year's meeting."

"I want these conversations to go on and on and on! They are so validating! Thanks for this community."
**Alliance Meeting**
The Alliance Meeting (November 22-23) welcomed over 200 representatives from our member associations. Through 20 presentations, they shared research and study results, online tools, diversity priorities, patient and caregiver care, as well as the role and activities of the Alliance in providing support. While inequities exist in the world with respect to ALS/MND research, access to quality healthcare and multidisciplinary clinics, and access to clinical trials, through meetings such as this one, we strive to create accessibility for all.

**Allied Professionals Forum**
The Allied Professionals Forum (December 1-2) attracted over 400 allied health professionals from 36 countries. With almost 30 presentations, some of the highlights included the evolution of voice banking towards natural voice and different languages, ethical considerations for genetics, quality of life concerns for people living with ALS/MND, and the burden of caregivers.

**ALS/MND Connect**
ALS/MND Connect (December 3) had over 1000 views. This live-streamed event connects people living with ALS/MND and their family and caregivers with leading international neurologists and researchers. This year featured Dr. Felipe Ocampo, who shared his journey as a person living with ALS/MND since his diagnosis in February 2021 and his efforts to increase awareness of the disease globally. We also heard from Professor Orla Hardiman who spoke optimistically about ALS research, Dr. Terry Heiman Patterson who looked at the role of genetics in determining treatment, and Dr. Angela Genge who discussed the current challenges and strategies for clinical trials.
We would like to extend a great big thank you to our sponsors for their support. These meetings could not have happened without them.
The 2021 Award Winners

Allied Health Professional Award

This year's winners are Dr. Melinda Kavanaugh and Sarah Solomon. Both are being recognised for the exceptional care they provide to people living with ALS/MND.

Dr. Melinda Kavanaugh is Associate Professor at University of Wisconsin-Milwaukee in the United States, where she is focussed on youth as caregivers, especially those acting as caregivers for family members with chronic illnesses including neurological disorders. The practical resources and programs she has developed with the ALS Association speak quite clearly to her commitment to advancing clinical care in ALS/MND.

“You only need to hear Dr. Kavanaugh present one time to see how passionate she is,” says Sara Feldman from the ALS Hope Foundation. “Her work on children as caregivers for people living with ALS/MND addresses an issue that has been overlooked for many years. She is dedicated to changing that and is sharing her knowledge and expertise with other health professionals, people living with ALS/MND and the young carers themselves. She saw a need and filled it with care, passion and enthusiasm, and we thank her for that with all of our hearts.”

Sarah Solomon is Senior Occupational Therapist at Calvary Health Care Bethlehem in Australia, where she assists other therapists with information and advice to help them to work effectively with patients living with ALS/MND. She is a strong advocate for the needs of people with ALS/MND and an active member of MND Victoria’s Equipment Reference Group, the Rehabilitation and Assistive Technology Association and the Palliative Rehab Special Interest Group in Australia, among others.

“Ms. Solomon is known for her ability to think outside of the box to come up with a solution that meets the needs of the person with ALS/MND whom she is working with or consulting about,” says Jo Whitehouse from MND Victoria. “She is a thought leader in the area of adjusting and adapting to rapidly changing function, and an expert on the assessment for and prescription of electronic assistive technology. She is a very worthy winner of this award.”
Humanitarian Award

This year’s winner is Canadian researcher Dr. David Taylor. This prestigious award honours Dr. Taylor’s dedication to enhancing the quality of life for people living with ALS/MND around the world. In his role as Vice President of Research at the ALS Society of Canada, he oversees the Canadian national research program, facilitating collaborations within and for the ALS/MND research community.

With the International Alliance of ALS/MND Associations, Dr. Taylor has been the chair of its Scientific Advisory Council (SAC) since 2018 and has built a group of 10 key opinion leaders from across the globe, who are focussed on finding viable breakthroughs in research and care options, and communicating them in an accessible and understandable manner.

“The Council is very important for all the patients and caregivers around the world because its members are the experts and provide a worldwide view on research and potential medicines,” says Gorrit-Jan Blonk, CEO of the Dutch ALS Foundation. “To get an opinion on those breakthroughs from the Council is much better than from only one country. The best care and a cure for patients will happen if we look from an international perspective, and that is what Dr. Taylor is coordinating as the chair of the SAC.”
Forbes Norris Award Winner

This year’s winner is Italian neurologist Dr. Adriano Chiò. This distinguished award honours his decades-long contribution to the management of and advances in understanding ALS/MND.

Dr. Chiò began studying patients suffering from ALS in 1988, opening the first dedicated clinic, the Torino ALS Center, at the University of Torino, Italy. Among his many accomplishments, he established a psychological support service with a particular focus on patient caregivers; helped initiate home care for patients living with ALS/MND; and championed the first Italian collaboration with palliative care units by organizing a specific care protocol in the advanced stages of the disease, which was instrumental in extending palliative care to ALS/MND patients. He also discovered several ALS genes and leads the Italian ALS Genetic Consortium.

Internationally, Dr. Chiò has actively participated on projects such as the longest-lived prospective population epidemiological registry on ALS/MND, which has been instrumental in increasing the understanding of the disease and improving patient care. He has also been a part of the most critical therapeutic trials on ALS/MND, and his scientific discoveries, together with the identification of several previously poorly understood aspects of the disease, have greatly improved the knowledge and clinical management of ALS/MND patients.

“Dr. Chiò is an outstanding personality in the ALS/MND world,” says Andrea Calvo, Associate Professor at the Torino ALS Center. “The combination of the highest level of research with the empathy of daily assistance makes him an exceptional actor. However, what makes him extraordinary is that he created a school. Many doctors and researchers have emerged following his teachings and carry on his passion in the fight against ALS/MND.”
Speaking Up for Our Rights

Advocacy & Support

As part of our priority to build capability, we look for ways to make our members stronger to advocate on behalf of people living with ALS/MND across the globe. This work is primarily carried out by the Scientific Advisory Council (SAC), the PALS & CALS Advisory Council (PCAC), the Innovation and Technology Advisory Council (ITAC), and our newest committee established in 2021-2022, the Advocacy and Public Policy Committee (APPC).

We are pleased to share some the concrete achievements these committees have accomplished over the past year to support our members:

• Fundamental rights:

We reaffirmed and continued to promote the Fundamental Rights of People Living with ALS/MND, which were developed in 2020. In 2021, the right to genetic testing and counselling at diagnosis was added. We also continued to advocate for the Fundamental Rights of Caregivers of People Living with ALS/MND, which were developed in 2021.

Our goal is to make it clear that everyone living with ALS/MND has the right to the highest quality of life, the highest quality treatment and the highest quality of care. We also want to ensure that caregiver burden is recognised.

The International Alliance of ALS/MND Associations supports the following fundamental rights for people living with ALS/MND worldwide.

Although the International Alliance and its representatives understand that some of these conditions might not be immediately attainable, this document represents the set of rights all Alliance member organisations should adopt and promote as conditions, systems and resources allow.

People living with ALS/MND have the right to:
1) highest quality care available within their healthcare system.
2) highest quality treatment available within their healthcare system.
3) information and education that will enable them to play an active role in making decisions.
4) choice with respect to:
   a) health and support workers who are providing treatment or advice
   b) the place where care takes place and
   c) the type of treatment or support that is provided.
5) choices include the right to accept, refuse, or discontinue treatment or intervention within the legal framework of one’s own country.
6) provide input on the healthcare and support system, including policy-making, care delivery and the implementation of medical research procedures and protocols.
7) the best quality of life possible.
8) live without discrimination.
9) assurance of confidentiality and privacy regarding their personal information.
10) upon diagnosis, have access to:
   a) up-to-date education about clinical genetics in ALS/MND.
COVID-19 vaccination:
We developed and shared a vaccine letter template with all member organizations to support their advocacy on behalf of people living with ALS/MND in the queue to receive vaccines.

Website:
We redesigned the Alliance website using a person-centred approach. This work was led by the members of the PALS & CALS Advisory Council, who shared real-world expertise on how they would like to interact with the information we provide online.

Voice banking:
We supported voice banking research and initiatives as a way to help people living with ALS/MND maintain their identity and their social and work networks. We also had presentations on this topic at the Allied Professionals Forum.
Global ALS/MND Awareness Day

Every year, we celebrate June 21 as the global day of recognition of ALS/MND — a disease that does not discriminate on the basis of race, ethnicity, socioeconomic status or region. There are people living with ALS/MND all over the world, and for every person diagnosed, the impact of the disease will be forever felt by their loved ones.

Thank you to everyone who made this year’s Global ALS/MND Awareness Day a remarkable success. Alliance members around the world used the hashtag #ALSMNDWithoutBorders to raise awareness and funds, and our international community rallied to the cause. Virtually and in person, we saw engagement from hundreds of thousands of clinicians, researchers, industry partners and, most importantly, people living with ALS/MND and their caregivers and friends.
Setting the Path for a Brighter Future

Member Research

The strength of any association is defined by its membership, and research is important to better understand our members and how we can support them and the ALS/MND community. In 2021, we conducted a survey based on the Alliance's Fundamental Rights of People Living with ALS/MND and Fundamental Rights of the Caregivers for People Living with ALS/MND.

The survey was translated into 10 languages and we received responses from 32 countries. The total number of responses was 1,086, which breaks down into 410 (38%) from people living with ALS/MND (PALS), 474 (44%) from caregivers for people living with ALS/MND (CALS) and 202 (19%) disqualified, as they responded "other" in the initial qualifying question.
For the PALS, the overall figures are low, with a median of 45% of Fundamental Rights being respected. Some specific findings that merit discussion are:

- The right to the highest quality of healthcare and treatments are at 49% and 44% respectively, which is concerning that neither are at 50%. What can be done to provide access to multidisciplinary clinics, approved treatments and clinical trials globally?

- The right to confidentiality and privacy is high at 75%, but this is an area that is highly legislated through mechanisms such as GDPR. Do other areas need to be legislated to have the right respected?

- ALS/MND can force people into poverty if they do not have access to remuneration (40%) and/or supplemental insurance (25%). This is an area our community has to advocate for!

- The highest drivers of PALS agreeing that they had access to the highest quality healthcare were access to a multidisciplinary clinic with a team of allied health professionals that specialise in ALS/MND. How can we make sure that more people with ALS/MND have access to these highly qualified professionals without adding additional burden to the individuals?

- Right to confidentiality and privacy is high at 75%, but this is an area that is highly legislated through mechanisms such as GDPR. Do other areas need to be legislated to have the right respected?

- The results for genetic counselling and testing are very low at an average of 33%. There is limited access worldwide. What can the Alliance and its member organizations do to help?
For the CALS, the figures are even lower, with a median of 30% of Fundamental Rights being respected. Some specific findings that merit discussion are:

Although 61% receive adequate education and access to resources, and 37% received counselling, less than 30% reported that they have time for themselves or for future planning.

Caregivers have little right to remuneration (27%), even less so than the PALS (40%). We know a person living with ALS/MND needs a high level of care, often requiring a caregiver to leave full-time employment. If there are no economic supports in place, this has a huge impact.

There is an overall feeling of not being listened to or having a voice. Caregivers are unable to provide input about their experiences or feedback on procedures and protocols at the individual level, or into public policy and healthcare at the community level.

These results give us a benchmark of the status of the rights of PALS and CALS globally, and the imbalances that exist. Armed with this knowledge, we have had conversations with member associations from some of the statistically significant countries, providing positive feedback on how this data can help them with their strategic direction. We will also use this information to identify the areas we should be focussing on when creating resources to support all our members in the worldwide fight against ALS/MND.
Ongoing Education

The strength and influence of our members and the ALS/MND community is dependent on up-to-date knowledge. That is why providing relevant and accessible education continues to be a priority. We have had tremendous feedback about our member roundtables and our webinars, the latter of which are designed for the general public who have an interest in ALS/MND. We continued both this past year, offering 16 in total.

Specifically, we identified research focussing on genetics as an impactful entry point to exploring ALS/MND. Genetics has largely fuelled our understanding of the disease, and with the exponentially increasing number of genetic variants being discovered, we hope that underlying biological pathways can yield knowledge to identify therapeutic targets that have significant effects for some, or all, living with ALS/MND.

In 2021, we created several resources on the topic of genetics:

- Introduction to ALS/MND Genetics
- Ethical Considerations for Genetics
- Genetics - Counselling and Testing

Webinars
Some people have a copy of a mutant version of the gene to be present for an autosomal recessive inheritance. The mutant version of the gene is called a variant DNA unit. A nucleotide variant is a portion of your DNA that differs from your reference genome. When a mistake in your DNA occurs, and results in a change in your DNA units (such as a nucleotide variant), a portion of your DNA may be deleted or inserted, or a small region of DNA may comprise a deletion or insertion. When your DNA is copied, mistakes can happen and this is a normal process.

When a mistake in your DNA occurs, and results in a detrimental outcome such as a disorder, this is called a genetic mutation. Some genetic disorders need two copies of a mutant gene to be present for an autosomal recessive inheritance. Some genetic disorders need just one copy of a mutant gene to be present for an autosomal dominant inheritance. People who have a copy of a mutant gene for an autosomal dominant genetic disorder are called carrier or affection carrier.

To make these building blocks, your body makes a photocopy of the required genes. Genes are important paragraphs interspersed throughout the book. Genes contain information for human traits and instructions to life. Your DNA is made up of 23 pairs of chromosomes which are the biological building blocks called RNA. The material has been adapted by Kristiana Salmon and Helmut Bernhard from a presentation given by Dr. Kelly Williams, Macquarie University, Australia.

When a mistake in your DNA occurs, and results in a detrimental outcome such as a disorder, this is called a genetic mutation. Some genetic disorders need two copies of a mutant gene to be present for an autosomal recessive inheritance. Some genetic disorders need just one copy of a mutant gene to be present for an autosomal dominant inheritance. People who have a copy of a mutant gene for an autosomal dominant genetic disorder are called carrier or affecion carrier.

To make these building blocks, your body makes a photocopy of the required genes. Genes contain information for human traits and instructions to life. Your DNA is made up of 23 pairs of chromosomes which are the biological building blocks called RNA. The material has been adapted by Kristiana Salmon and Helmut Bernhard from a presentation given by Dr. Kelly Williams, Macquarie University, Australia.

We will continue our efforts to increase awareness and understanding of ALS/MND among our members and the general public at the local and global levels, as ALS/MND truly is a disease that knows no borders.

We know we cannot do it alone. We would like to thank all of our volunteers who give generously of their time and energy to the International Alliance of ALS/MND Associations. Our Board of Directors, Advisory Council members, committee volunteers and engaged members like you are vital to our success as we work together to create a world free of ALS/MND.

We would also like to recognize all the people living with ALS/MND and their families and caregivers across the world who give in so many ways to the Alliance. Thank you for all you are doing in this fight and daily battle.