



COVID-19: IMPACT ON PALS & CALS ROUNDTABLE



COVID-19: IMPACT ON RESEARCH AND CLINICAL TRIALS GLOBALLY AND RISK FOR PEOPLE WITH ALS/MND

On Wednesday, April 22, 2020 two roundtables were hosted by the PALS & CALS Advisory Council (PCAC) of the International Alliance of ALS/MND Associations. COVID-19 and its impacts to the ALS/MND Community have been felt globally and the impacts to PALS & CALS has been profound. People living with ALS/MND spoke to what is currently happening both in their personal stories with ALS-MND and how their regions/countries are responding to the COVID-19 pandemic.

Moderator: Cathy Cummings, Executive Director, International Alliance of ALS/MND Associations

Welcome: Calaneet Balas, Chair, International Alliance of ALS/MND Associations

PCAC Members:

Sara Feldman, Chair

Carol Skinner

Doug Clough

Phil Green

Bruce Virgo

Angelique van der Lit - van Veldhuizen

Marcela Santos

Gudjon Sigurdsson, Board Liaison

VISION: A World Free of ALS/MND

PURPOSE: The Alliance is a global network of ALS/MND associations informed by PALS/CALS, that builds capability for its members and connects to external stakeholders.



Introduction: We have never faced anything like this in the world before and we at the International Alliance (IA) want to make sure that people living with ALS/MND remain a priority. Whether it is clinical care, research, clinical trials, global collaboration, or education, we want it all to continue. That is why we hosted these roundtables, so that we could hear from our PALS and CALS community the same way that we have heard from clinicians about Care and Research. For those of you who were at the meetings in Perth Australia in December, there was a lot of hope and optimism at those meetings - 2020 was going to be an exciting year. We really want to keep that momentum moving in the ALS/MND community, despite COVID-19. We know there are other priorities, but we don't want ALS-MND to be deprioritized. ALS-MND doesn't stop and neither do we!

The International Alliance has the same vision as everyone on this call; a world free from ALS/MND!

In all the work we do, we want the work to be informed by people living with ALS/MND and their caregivers. We are a global gateway between external stakeholders and our membership. We have 3 councils that are fundamentally important to what we do. The PALS and CALS Advisory Council (PCAC) who are hosting this roundtable; the Scientific Advisory Council (SAC) which is responsible for advising the Board of Directors on scientific and biomedical matters; and the Innovation and Technology Advisory Council (ITAC) whose mandate is to advise the Board of Directors on technologies that will benefit people living with ALS and MND. The PCAC, has the mandate of helping the Board of Directors of the International Alliance consider and include in its mandate the wide-ranging opinions and ideas of people living with ALS /MND and their caregivers, from all across the globe. The 3 advisory councils integrate with each other and the Board of Directors so that we make the best possible strategic decisions as an Alliance.

Although the roundtables were at different times and had varied participants, some common themes emerged which are outlined below, in no particular order.



Telemedicine: Every person that spoke has been using telemedicine in some way during the COVID-19 period. Our health systems infrastructure has been forced to adapt in a very creative and urgent way and there is overwhelming support that virtual connection should be here to stay when it makes sense in the care journey for people with ALS/MND. Telemedicine allows people to access multidisciplinary care in an easy and efficient way, which is an effective use of resources for both people who would otherwise find traveling to a centre challenging, and for people who do not have centres in their region to travel to. Telemedicine can make the whole system more efficient and can be used both as doctor – patient, and doctor – doctor where regulatory jurisdictions are a barrier.

Telemedicine should also be used where possible for clinical trials. Often it is unnecessary for someone to travel by plane or car for a test that can be done over the phone or by other technology such as Zoom or SKYPE.

Technology for connection: In addition to telemedicine, technology should be used for social interaction, including support groups. This has been proven to be helpful during this time of physical distancing, but will continue to be a good tool for connecting PALS and CALS both locally and globally in the future. This is an opportunity to reach more individuals than possible if meeting in person only. Many individuals mentioned that they had been contacted by their ALS or MND association and that they felt the proactive check in to see if they were ok was very helpful to feeling supported.

Resources: A question arose about where to get resources for people living with ALS/MND during COVID-19. Many associations have gathered resources and put together videos, roundtables, and webinars, that can be viewed on their websites. The International Alliance of ALS-MND Associations has posted links to some of these resources, and it is encouraged for people to look at various ALS-MND websites internationally for updates on care, research, support, and connection. You can use the International Alliance website as a gateway to all of these resources in two ways – you can click on the red bar that says Coronavirus (COVID-19) update for the resources we have gathered or click on the Find An Association menu item and look for resources by country. The website is: www.alsmndalliance.org



 [Members' Login](#)

[What is ALS/MND?](#) [Events](#) [Find an Association](#) [Support for Members](#) [Advocacy](#) [Global Day](#)

[Click here for Coronavirus \(COVID-19\) updates](#)

Find ALS/MND associations around the world

Search

Region

-- select a Region --

Country

Map

Satellite



Susceptibility: A question was asked about susceptibility and COVID-19 and it was noted that this came up on both of the webinars done by the Alliance in the two weeks preceding - those can also be found at the Alliance website mentioned above.

Policy: A topic that had a lot of traction on both calls was that this community has been fighting for changes to policy, and that process has been slow, but COVID-19 has demonstrated that this does not always have to be the case. Pathways to quick policy changes and approvals should be created for ALS/MND similar to the way they were expedited for COVID-19. One participant phrased it well when he said that we “need to be ready for when COVID-19 begins to come to a close, hopefully with a vaccine, that we will keep those pathways to policy open so that we can affect change quickly for the ALS/MND community.”

Respiratory Equipment: The biggest concern raised on the calls was the de-prioritization of respiratory equipment for ALS/MND patients that is happening in some areas of the world. Some jurisdictions are experiencing price gouging, others lack of availability, and even where this is not the case, there is underlying concern that COVID-19 is diverting respiratory equipment. That being said, there was also a silver lining in the USA when a decision was taken



to not have non-invasive ventilators come up for bid in 2021. The ALS Association has been fighting for that legislation for a long time and despite the fact that this was due to COVID-19 it is a win for ALS.

Personal Protective Equipment (PPE): The shortage of PPE is troubling for many who joined the roundtables especially for those that have external caregivers come into the home. Since prevention is the number one strategy for risk, the lack of PPE is very concerning.

International Meetings: A question arose about the International Alliance Meeting, the Allied Professionals Forum, and the Research Symposium, and their viability in Montreal in December 2020. Sally Light, CEO of the MND Association who hosts the Symposium said, “it’s a big consideration about the symposium because who knows what the world be like when we get to December and if people will be able to travel, so we are thinking about that at the moment and as soon as we are able to make a decision we will communicate to the community as quickly as we can. Its such an important part of year. The virtual environment does create additional opportunities because we are able to get in touch with more people that we might have been able to do otherwise. We will let you know as soon as we can.”

Fundraising: Another thing that was mentioned was the ability of funders of research and clinical trials ability to raise money in this environment. One PALS said “what has happened is that large fundraisers that they rely on as serious income sources for their entire year have had to be postponed and that impact has forced organizations to be creative.” Many associations are moving their fundraising to virtual platforms, including walks, runs, trivia, and other challenges that our community will still want to participate in both to raise money and awareness. There was some concern from PALS & CALS that this would impact research funding down the road.

Access to therapies: There are many therapists that ALS/MND patients see, including, but not limited to, physiotherapists, respiratory therapists, physical therapists, etc. and those individuals are not coming into homes now and are relying on individuals and family members to execute on their instructions via telemedicine. There was some concern expressed that this would impact quality of life since things like hydrotherapy can only be done outside of the home.

Caregivers: Caregiver mental health, burnout and stress was a major concern raised on the calls. Since many are restricting caregivers to only those that live in the home there are many additional stressors that have been added to families. Caregivers have had to add to their skill sets to be able to work from home themselves in many cases as well. Under the old maxim ‘necessity is the mother of invention’, caregivers have been called on to do additional duties



such as home schooling for kids, cutting hair, setting up computers and dealing with technology issues to name a few.

Hospital Restrictions: Almost all hospitals globally have restrictions on visitors and additional caregivers at this time, which is extremely challenging for any ALS/MND patient that is admitted to hospital, particularly if there are communication issues. It was mentioned on the roundtables that “the nurses don’t have time because they have to care for many patients at a time, so they can’t sit down and help patients communicate and this has led to symptoms of depression.”

Physical Distancing: It is important to emphasize the difference between Physical Distancing and Social Distancing – just because we are physically distanced doesn’t mean we have to be socially apart and that is a concept that should exist long after the pandemic is over for PALS and CALS who need social connection despite being in isolation.

Path to empathy: Another thought that was expressed multiple times was that the rest of the world can now relate to the challenges of people living with ALS/MND. For those living with ALS-MND, often isolation already occurs, and this is something that PALS and CALS have learned to work with and around, using technology and resources to accommodate and connect. This pandemic has given the rest of the world an opportunity to see what that social isolation feels like, to empathize with those who have been isolating for various reasons before this point, and will continue to have to isolate after.



On our second roundtable, Norman MacIsaac, from Montreal, Canada shared a passage he had written:

Hidden behind the pandemic, we survive, thrive or die with this disease.

Back when the streets were packed, we stayed home for our own reasons.

Perhaps because of the snow and ice.

Possibly because our energy did not suffice.

As the world buzzed, we barely hummed.

As they rushed, we hobbled.

As they rattled off words like newspapers emerging effortlessly from the press, we struggled just to be understood, stumbling over words and slurring like the drunk at the local pub.

One thing's for sure: We've been here before, and we will still be here, "confined", after this pandemic ends.

So, we should be proud and confident.

We are all that Brené Brown would want us to be.

We are vulnerable but we are strong.

Because we are the masters of this battlefield.

We know about confinement more than the general public will ever comprehend.

We all face an uncertain future, but those of us living with this disease are better prepared.

We've already looked death in the eye.

We know about the importance of just being there.

And that confinement is just a state of mind.

Author: Norman MacIsaac