



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

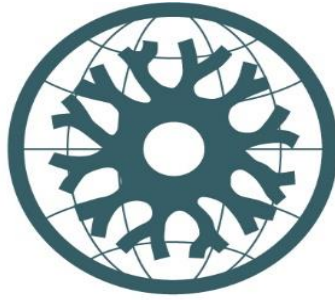
Alliance Meeting Programme

4th – 5th December 2018 | Glasgow, Scotland, UK

This event is sponsored by:



Cytokinetix



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

26th Annual Meeting
 Tuesday and Wednesday, 4 and 5 December 2018
 Crowne Plaza, Glasgow, Scotland
Programme Agenda

Tuesday 4th December

08:30	Welcome and Introduction		
09:00	Annual General Meeting		
10:15	Welcoming our new members		
10:30	Morning Refreshments		
	Presentations on Advocacy		
11:00	Introducing an Advocacy Service	Roslyn Scholarios	MND Scotland
11:15	10 years of NDIS influencing: Contributing, Collaborating and Communicating to ensure early intervention and needs based supports for people living with MND	Carol Birks	MND Australia
11:30	The United States National Amyotrophic Lateral Sclerosis (ALS) Registry Advances research Domestically and Internationally	Paul Mehta	USA
11:45	ALS Centres in France	Christine Tabuenca	ARSLA
12:00	Advocacy and Voluntary Assisted Dying	Rod Harris	Australia
12:15	From side of desk to front of mind: Accelerating advocacy to meet the need	Tammy Moore	ALS Canada
12:30	Lunch	Marina Restaurant	
	Presentations on Programming for PALS/CALS		
13:30	Creating Educational Videos	Craig Stockton	MND Scotland
13:45	Online support – new tools to expand reach without expanding the budget	Efrat Carmi	IsrALS
14:00	Challenges in India for Caregivers of ALS Patients	Ajay Gupta	Asha Ek hope Foundation

14:15	Project Revoice: Assistive technology to ensure people with ALS/MND are always heard	Brian Frederick	ALS Association
14:30	The diversified service and awareness campaigns of ALS Liga Belgium and how it achieved by efficient use of limited financial and human resources	Evy Reviere	ALS Liga Belgium
14:45	Introduction of communication support activities in Japan	Katsushi Tamaki	Japan ALS Association
15:00	Refreshments		
	Presentations on Partnerships		
15:30	Project "ANDAR"	Pablo Aquino Dario Ryba	Asociacion ELA Argentina
15:45	Together we're strong! The Dutch approach	Theo Meister	ALS Patients Connected
	Presentations on Stakeholders Engagement		
16:00	Improving MND Care Survey	Nick Goldup	MNDA
16:15	Blink to Speak – World's first Eye Language	Geet Rathi	Asha Ek Hope Foundation
	Presentation on Organisational Development		
16:30	A cause of all	Adriana Oda	ABrELA
16:45	Nina Levitskaya Russian Charity ALS Foundation: Advances after the 10 th Anniversary	Gleb Levitsky	Nina Levitskaya Russian Charity ALS Foundation
17:00	Networking in Lobby		
18:30	Pre-Dinner Drinks Reception	Castle Foyer	
19:00	"Warm and Fuzzy" Dinner	Castle Suite	



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS



Cytokinetics



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

26th Annual Meeting
Tuesday and Wednesday, 4 and 5 December 2018
Crowne Plaza, Glasgow, Scotland
Programme Agenda

Wednesday 5th December

09:00	Strategic Plan Presentation	Tammy Moore	
11:00	Refreshments		
11:30	Scientific Update	Dr David Taylor	ALS Society of Canada, Alliance Scientific Advisory Committee
12:00	Invitation to Perth 2019		MND Australia
12:10	Thank You & Close: Meeting Adjourns (Group Photo)		
12:30	Lunch	Marina Restaurant	
12:00 – 14:00	PALS/CALS Lunch	Island Suite	
14:00	Ask The Experts		
18:00	Cocktails followed by Host Dinner	Castle Foyer	

Alliance Meeting Programme Committee

Efrat Carmi, IsrALS, Israel
Sara Feldman, The ALS Hope Foundation, USA
Tammy Moore, ALS Canada



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS



Presentation Abstracts – Alliance Meeting 2018

ADVOCACY 11:00am

- **Speaker** Roslyn Scholarios
- **Member Association** MND Scotland
- **Title of Presentation** Introducing an Advocacy Service
- **Theme** Advocacy
- **Abstract** MND Scotland developed an Advocacy Service based on its research identifying many of the key difficulties being faced by people with MND and their families when trying to access social care or community health services. These key difficulties included:
 - Not knowing where to go to get the help that they needed
 - Having problems with the practical aspects of having to make phone calls, and other contact, with social workers and other staff who deal with requests for help
 - The additional stress people experienced when dealing with a complicated system that has poor internal communication
 - People feeling that they are dealing with these problems on their own and there is no-one to help them
 - People feeling that their views and wishes were not being properly considered when decisions were made about their care and support needs

Until the introduction of the new service, a range of MND Scotland staff were doing their best to respond when people living with MND, or their families, asked for help. The main difficulty for staff, both in the Policy team and other colleagues, was the challenge of taking on a problem that was often both immediate and very time-consuming in between doing other work.

Now that it is in place, our Advocacy Service provides a more effective link between people affected by MND, their MND Clinical Specialist and local services.

Our advocacy team are the key contacts to help with accessing social care, adaptations and equipment to enable people affected by MND to live as full a life as possible in their own homes.

In particular, the service is there to support people affected by MND in ensuring timely referrals are made to social services and care agencies, and to work alongside local integrated health boards in achieving a seamless service.

Our team work closely with people affected by MND to try to resolve any issues they are having, and take some of the stress away from dealing with these. Our Advocacy Workers can speak to organisations on their behalf to make the process easier for them.

We are able to help with a variety of problems, for example:

- Accessing services from local authorities
- Accessing free personal care
- Getting home adaptations
- Moving to more suitable housing
- Accessing care packages
- Issues with insurance companies

This service is available across Scotland and can be delivered face-to-face, depending on location, or by phone or email.

The benefits that people living with MND, and their families, are likely to gain from our service include:

- Taking some of the pressure and stress away from them and their family

- Making sure they are given the care and support to which they are entitled
 - Ensuring that they do not feel like they are dealing with issues alone
 - Allowing people with MND and their families to spend more time on activities that matter to them, rather than trying to resolve problems
 - Making sure that their voice and choices are heard.
-

11:15am

- **Speaker** Carol Birks
- **Member Association** MND Australia
- **Title of Presentation** 10 years of NDIS influencing: Contributing, Collaborating and Communicating to ensure early intervention and needs based supports for people living with MND
- **Theme** Advocacy
- **Abstract** The idea of a National Disability Insurance Scheme (NDIS) was first introduced at the 2020 Summit held in Canberra in 2008. MND Australia immediately recognised the NDIS as a once in a lifetime opportunity to transform the lives of people living with motor neurone disease (MND). MND Australia has therefore worked in partnership with its members, the six state MND Associations, to influence the establishment of a scheme that would ensure people living with MND receive the supports they need to maintain their independence, social inclusion and quality of life.

Influencing government policy is a long-term commitment requiring determination, flexibility and patience. Over the last 10 years we have worked with a clear focus to ensure recognition of MND as a rapidly progressive, complex condition requiring a rapid and coordinated response from diagnosis onwards. From the outset we have advocated that all people with a diagnosis of MND should have early access to individualised needs-based support no matter their age or postcode.

MND Australia contributed to the initial productivity inquiry report which was delivered to the government in August 2011 and has since written many related submissions, appeared at public hearings, developed position statements, met with the NDIA and relevant Ministers and Opposition Spokespeople and collaborated with like organisations to promote our collective issues. We have worked nationally with the MND community to communicate the support needs of people living with MND through campaigning and Parliamentary events.

The NDIS started as a trial in July 2013 in four sites in NSW and Victoria. The MND Associations of NSW and Victoria have been actively involved in these sites advocating for individuals, educating local NDIA staff and working to improve NDIA understanding of the progressive and terminal nature of MND within a model focused on capacity building. Since then the NDIS has rolled out in more regions and has commenced roll out in other states.

So, are we there yet? Some NDIS participants living with MND have received plans that are having positive, life-changing impacts on their lives and the National Disability Insurance Agency (NDIA) has recently introduced a range of measures to educate NDIA staff on the unique needs of people living with MND as a direct result of our sustained advocacy. However, as the scheme continues to roll out in new areas with new NDIA staff many struggle to receive plans in a timely manner that take their progressing and complex needs into account. Our collective influencing must therefore continue.

MND Australia works to improve the lives of all Australians impacted by MND by influencing policy, providing trusted information, raising awareness and funding the best research. Whilst the search for an effective treatment for MND continues we remain focused on improving access to the support people living with MND need to maintain their independence, social inclusion and quality of life – until there is a cure there is care.

11:30am

- **Speaker** Paul Mehta
- **Member Association** CDC, ALS Association invite
- **Title of Presentation** The United States National Amyotrophic Lateral Sclerosis (ALS) Registry Advances Research Domestically and Internationally
- **Theme** Advocacy
- **Abstract** The National ALS Registry maintained by the Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry (CDC/ATSDR), is the largest database of persons with ALS in the United States. One of the purposes of the Registry, as defined by Congress, “is to facilitate research.” In addition to registering patients with ALS and collecting epidemiological data, a National Biorepository was added in 2015 after the completion of a pilot project. The purpose of the Biorepository is to expand ALS research in areas such as genetics, biomarker identification, environmental exposures and disease progression. Because recruiting interested PALS can be difficult and time consuming for researchers, the registry can assist with recruiting people with ALS into clinical trials and research studies. The registry can also provide de-identified self-reported epidemiological data and/or biological samples for a subset of persons in the registry.
Design/Method: CDC/ATSDR developed mechanisms that allow eligible persons with ALS to be informed about clinical trials and research studies, provide specimens to the Biorepository and self-report epidemiologic data securely. Researchers can apply to receive data from the registry and/or samples from the Biorepository as well as have recruitment emails sent for their studies. Researchers who want to use one of those mechanisms submit an application to CDC/ATSDR with information about the study and provide documentation that an Institutional Review Board has approved the study. CDC/ATSDR maintains a scientific review committee.
Results: Over 35 institutions (pharmaceutical companies and academia) have used the Registry to recruit for their clinical trials and studies. Analyses have been completed for the Biorepository specimens (blood, urine, serum and saliva) for the following areas: heavy metals, persistent organic pollutants, and genotyping. Almost 40 patients have completed a post-mortem component, which covers whole brains, CSF, spinal cord and tissue. Data is available for researchers from 17 risk factor modules, (demographic, occupational, military history, physical activity, smoking/drinking, ALSFRS, clinical onset, etc)
Conclusions: The National ALS Registry provide researchers to a large national group of ALS cases and data for their research nationally and Internationally.

11:45am

-
- **Speaker** Christine Tabuenca
 - **Member Association** ARSLA
 - **Title of Presentation** ALS centres in France
 - **Theme** Advocacy
 - **Abstract** At the instigation of ARSLA and health care professionals, the Ministry of Health has set up a device recognizing the specified management of rare diseases. The first National Rare Diseases Plan was initiated in 2005 with the aim of meeting the support needs of sick people, improving their access to care and the quality of care. It was also about improving information to patients, training professionals, epidemiological knowledge, and promoting research.

This plan allowed the identification of 16 reference centres for the care of PALS to ensure equal access to care on the French territory.

A second plan continued the action : one of its results was the creation of the ALS and other Motor Neurone diseases sector in 2014, with its mission of standardizing the practices by guaranteeing a continuum between the various actors of the field of ALS: professionals of the social medico, neurologist, researchers...

The objective is to exchange, pool and federate all the actions that contribute to better management of PALS and their caregivers. ARSLA is also involved. The ALS sector also has training and information missions.

A 3rd plan is in preparation.

The Ministry of Health launched a national request for proposals on June 2017 to update the 2005 scheme for the identification on the national territory of a "network" of accredited expert sites dedicated to ALS.

After evaluation by a national jury, 19 centres were labelled in December 2017, for 5 years. These are expert centres, spread all over the territory, ensuring at least regional attractiveness, with the objective of territorial equity of care in terms of access to diagnosis, treatment, follow-up and overall care of the PALS. Reference Centres were also asked to have demonstrated specific expertise in the areas of research and training.

This label guarantees for all PALS a gathering of all health care professionals specialized in ALS: neurologist, specialized nurse, occupational therapist, nutritionist, speech therapist, physiotherapist

...

Labelled centres include access to diagnostic techniques such as specialized imaging, biological and molecular genetic analyzes, and assessment techniques for motor, nutritional, respiratory and neuropsychological impairments.

They also integrate partnerships of multidisciplinary skills in the areas of care or technical activities not directly related to their medical specialty (pneumology, rehabilitation medicine, palliative care ...) and provide privileged links with sectors specialized in compensation of disability through social assistance and specific equipment.

The professionals of the centres are invited to annual trainings in the fields of the evolution of the procedures of care and the update of knowledge in research.

12:00

- **Speaker** Rodney Harris
- **Member Association** Individual member
- **Title of Presentation** Advocacy and Voluntary Assisted Dying
- **Theme** Advocacy
- **Abstract** MND Victoria neither supports nor opposes such legislation, but has a policy to “support patient’s rights in all things that are lawful”.

To secure the rights of people living with MND in legislation regarding voluntary assisted dying, it is essential to be a part of the discussion around creating the legislation, identify weaknesses or issues that do not sit well with MND and its impact on people, propose alternatives to overcome those weaknesses, and to ensure that the rights of people who wish to exercise their rights under the Legislation are able to do so. That includes people who need to be protected and those who wish to use the legislation.

This presentation will identify the key issues we fought on, the reasons why, and the success we achieved. The presentation will not address whether we should or shouldn’t have this legislation – MND Victoria has no view on this. In Victoria, those that were elected to Parliament made that decision – our role was to ensure that the rights created were available to all people who meet the eligibility criteria.

Take Home Message

- organisations must consider the views of their membership – we represent very broad churches
 - positions must reflect the community of interest
 - advocacy must be about rights created
 - solutions to weaknesses must be deliverable
 - keep membership informed
-

12:15pm

-
- **Speaker** Tammy Moore
 - **Member Association** ALS Canada
 - **Title of Presentation** From side of desk to front of mind: Accelerating advocacy to meet the need
 - **Theme** Advocacy
 - **Abstract** At the 2017 Annual Alliance Meeting, ALS Canada presented the organization's new strategic plan and the collaborative and consultative process undertaken to develop it. Throughout the development of the strategic plan, it became clear that a stronger focus on advocacy would be required in order for the organization to maximize its impact and best serve the needs of the ALS community.

Faced with a new drug in regulatory approval, a motivated community calling on the government for increased ALS research funding, and access to a caucus of elected officials interested in supporting the ALS cause, ALS Canada had to quickly ramp up its internal resources to provide the necessary leadership for ALS advocacy in Canada. Within a 12-month period the organization has developed a strategic advocacy framework, engaged internal and external stakeholders as partners in advocacy, and moved proactively to advance critical, emerging and time-sensitive files within its advocacy portfolio.

The presentation we are proposing will provide insights into developing an in-house advocacy function based on ALS Canada's experience and share initial keys to successes and lessons learned along the way — including "be careful what you wish for!" It will include the role that stakeholder engagement, both internal and external, has played in building our advocacy function and identify how advocacy plays a critical role in our future direction.

Programming for PALS/CALS

13:30

-
- **Speaker** Craig Stockton
 - **Member Association** MND Scotland
 - **Title of Presentation** Creating Educational Videos
 - **Theme** Partnerships and Collaborations
 - **Abstract** MND Scotland has developed a short run of educational videos aimed at people with MND and their family carers. These videos represent a first step in our commitment to develop new high quality, accurate and accessible information that meets the needs of those affected by MND and allows them to make informed decisions.

The initial three clinical topics were chosen, in collaboration with the MND clinical specialists, based on evidence gathered from the MND register and NHS Lothian outlining some of the key clinical issues facing people with PWMND.

The aims of these chosen topics were:

Fitting a feeding tube

- To encourage patients to consider having a feeding tube fitted as soon as possible - to break down the barrier of patients thinking they “don’t need it yet”.
- To make patients aware of the pros and cons of feeding tubes so they can make an informed decision, and provide information on alternative options.
- To reassure family members that care of a feeding tube won’t be a problem.

Trips and Falls

- To decrease the number of MND admissions to hospital as a result of falling.
- To reduce the number of MND falls in the community.
- To provide guidance and tips for how to prevent trips and falls.

Choking

- To prepare family members for the situation where a person with MND is choking and provide coping mechanisms.
- To encourage both people with MND and their family members to remain calm during a choking episode and reassure them that it will pass.

The decision was made to produce animated videos with audio tracks consisting of testimonials from real people with MND, and their carers, who have direct experience of the specific topics covered. This peer to peer approach means that those watching the videos would be benefiting directly from the experiences of people who have been in these situations and would, therefore, have more impact than if we had used a generic voice actor. Written materials will be available to accompany each video once they are officially launched on our website.

13:45pm

- **Speaker** Efrat Carmi
 - **Member Association** IsrALS
 - **Title of Presentation** On line support- new tools to expand reach without expanding the budget
 - **Theme** Programming for PALS/CALS
 - **Abstract** Over the last decade IsrALS has spent time and resources on developing support services for the benefit of the 600 PALS and their family members in Israel. A staff of four social workers meets the patients in the ALS clinics, at home visits, run support groups and interact with the families on a regular basis. Unfortunately, some of the families cannot take part in support groups or other gatherings due to geographical distance and mobility problems.
Two years ago we opened a Facebook group that we manage. We have over 800 members in this group. They ask questions and get answers, either from their peers using the wisdom of the community or from our team of experts that are all also members in this group. It is a huge success and has turned out to be our main communication interface with our families. There is no doubt this group provides a support system to its members and in many ways substitutes for the need for real life interactions.
Recently we started a new innovative format of online text-only support groups. We use the 7chairs platform and run a few different support groups. Each group has 6 participants and a mentor, who is one of our social workers. All our social workers went through training to use the platform and on the main principles of running a text-only support group.
Two online text-only groups are for PALS, who use any communication system or device such as eye gaze, head mouse etc. It enables them to interact with other PALS in a similar condition, bridging any obstacle of distance or mobility. We also run two groups of family members and spouses. One of them is for Arab women who are coping with their husbands' disease and it is run in Arabic.
Using advanced technologies and thinking out of the box expanded the reach of our support services and enabled more PALS and family members to benefit from our support network, thus overcoming distance and mobility hurdles.
-

14:00pm

- **Speaker** Ajay Gupta
- **Member Association** 1870
- **Title of Presentation** CHALLENGES IN INDIA FOR CAREGIVERS OF ALS PATIENTS
- **Theme** Programming for PALS/CALS
- **Abstract** ALS/MND is a high demand medical condition where 24 hours involvement of care givers is required. They not only have to offer physical help but also cater to the emotional, social needs and bear huge financial burden. At the same time, they also have to take care of the other members of the family. In India due to lack of medical insurance coverage, all the expenses are out of pocket. It is a huge challenge to meet medical expense for patient's medication, nursing, personal care, equipment, rehabilitation therapies from regular earnings of the caregiver. If the patient is a sole earning member in the family then the situation becomes worse for the caregiver as there is no disability insurance in India.

Due to limited availability of trained doctors, therapists and nurses for ALS, caregiver does not get continuous guidance. ALS/MND patients need continuous motivation and counselling which requires caregiver's substantial time on daily basis which can be challenging in background of high demand of job or career advancement. Many a times caregivers have to find their own way to tackle day to day symptomatic issues faced by the patients of ALS/MND. Doctors are unable to do home visits and taking the patient to the hospital is also a big challenge.

As there is lack of awareness about ALS/MND in the society, caregiver has to repeatedly explain about the condition which is socially, and emotionally challenging. Caregivers also have to overcome some social stigmas and negative cultural beliefs. In summary, there are multiple challenges that a caregiver faces due to typical conditions in India.

Asha Ek Hope Foundation continuously strives to empower PALS/CALS to overcome the above challenges. We run various programs to tackle these issues. Some of the programs are ALS/MND center offering concessional Rehabilitation services, Psychological counselling, free doctor consultation, free Rilutor program, Equipment switch program etc. Awareness programs include distribution of free Guidebooks to PALS/CALS, Educational seminars, Motivational talks, Newspaper articles, Social media posts and ALS/MND mobile app. Future planning is to work on advocacy to government and healthcare system in India for medical insurance and disability coverage to ALS/MND patients.

14:15pm

- **Speaker** Brian Frederick
- **Member Association** The ALS Association
- **Title of Presentation** Project Revoice: Assistive Technology to Ensure people with ALS/MND are always heard.
- **Theme** Programming for PALS/CALS
- **Abstract** In the Spring of 2018, The ALS Association, working with an Australian creative agency and a Canadian technology company (Lyrebird) recreated the voice of the Ice Bucket Challenge co-founder Pat Quinn, using old interview clips. Quinn had lost his voice before voice banking, a common situation for many people with ALS. The initiative was designed to raise awareness of ALS and the importance of voice banking. The result of the collaborative effort was a synthesized “revoice” that sounds remarkably like Quinn – a fact underscored by the reaction of his friends and family when it was shared with them. The ALS Association’s awareness campaign generated global media coverage of ALS/MND and the campaign eventually won 6 Cannes Lions including the Gran Prix for Good and 7 Clio’s. This presentation is an example of developing and implementing assistive technology with help from a disease advocacy organisation. This presentation will provide a background of how Project Revoice came together and the challenges along the way, before previewing what lies ahead for the initiative. The discussion will touch on the current state of augmentative communication, how Project Revoice fits into this space, and the communication and implementation steps necessary to roll out new assistive technology. The ALS Association created projectrevoice.org to raise awareness and provide a place for people with ALS/MND to learn more about the issue. In reviewing the landscape of augmentative communication, it was clear that more concise, easy-to-understand information was needed. The ALS Association, working with assistive technology specialists, worked to educate people with ALS/MND about the various voice banking/voice synthesis services. These materials will be shared during the presentation. The next phase of the Project Revoice is to create a custom website that enables people with ALS/MND to more easily use their Lyrebird compared to the public-facing version of Lyrebird’s site.

14:30pm

- **Speaker** Evy Reviere
- **Member Association** ALS Liga Belgium
- **Title of Presentation** The diversified service and awareness campaigns of ALS Liga Belgium and how it achieved by efficient use of limited financial and human resources
- **Theme** Programming for PALS/CALS
- **Abstract** The ALS Liga Belgium has over 20 years of experience in supporting the ± 1.000 pALS in Belgium. We offer pALS, their families and friends a diversified service based upon 4 pillars:
 - (1) Stimulating and financing scientific research on ALS
 - (2) Providing direct support
 - (3) Defending the rights of pALS at governments and agencies, and aiming at customised care
 - (4) Providing free of charge high tech aid goods for mobility and communication.

Also, we regularly launch ALS awareness campaigns for the general public, that are coupled to fundraising. For instance, in 2018 our campaign 'Work for ALS' was very successful. In this campaign, ALS patients solicited at companies to (virtually) work for them again, donating their wages to ALS-research.

An overall view of our activities and recent ALS-awareness campaigns will be presented, with focus on how they are achieved by efficient use of limited financial and human resources.

14:45pm

-
- **Speaker** KATSUSHI TAMAKI
 - **Member Association** Japan ALS Association
 - **Title of Presentation** Introduction of communication support activities in Japan
 - **Theme** Programming for PALS/CALS
 - **Abstract** As you know, ALS causes severe communication disorders due to bulbar paralysis and the wearing of mechanical ventilators. Communication impairment not only bring down the patient's own QOL but also increases the burden on caregivers. The aichi prefectural branch of JALSA has visited patient's homes and hospitals for many years and has been engaged in communication using devices and the adaptation of switches. We also provide education programs for supporters. I think supporters are required to have "Courage and preparedness".
I can say that assessment at the start of our support and continuing support are very important in a patient prognosis. Today I will introduce the Japanese communication support system, how to organize supporters, what kind of support is being done, and what are the key points for support in my experience.
-

-
- **Speaker** PABLO AQUINO
 - **Member Association** ASOCIACION ELA ARGENTINA
 - **Title of Presentation** PROJECT "ANDAR"
 - **Theme** Partnerships and Collaborations
 - **Abstract** At the beginning of 2016, we got in touch with our peers from the ALS Association in Belgium as regards their wheelchairs donation program for other ALS/MND Associations in the world.

After an arduous customs process at international and local level, we received 10 imported electric wheelchairs in November of that year.

From that moment, we started our "ANDAR" Project. "Andar" means to "move" or to "march". We establish agreements with local medical insurance providers, which only involve the administrative import costs. At the same time, a free-use loan agreement is signed with the patient, through which they commit to keep the chair in optimum conditions and to return it once they no longer need it. The result of this program is much better quality of life and more autonomy for ALS patients at no cost for them. These chairs have the necessary technological efficiency, adapted to a disease as rare and complex as ALS.

Medical insurance providers are obliged by Law to cover this benefit. They incur in very little costs compared to the market price of these state-of-the-art power wheelchairs.

All of the 10 power wheelchairs were already assigned to specially selected PALS from different parts in Argentina. We have travelled many miles throughout this vast country to deliver. 15 more wheelchairs are currently on the way, thanks to a new donation from our sister Organization in Belgium.

A testimonial video production will be presented to share this program with all the Alliance members.

-
- **Speaker** Theo Meister
 - **Member Association** ALS Patients Connected
 - **Title of Presentation** Together we're strong! The Dutch approach
 - **Theme** Partnerships and Collaborations
 - **Abstract** In the Netherlands there used to be an ALS research and treatment center (the ALS Center, which was founded 15 years ago under supervision of Leonard van den Berg) as well as a fundraising organisation (ALS foundation, which was founded 9 years ago. The last 4,5 years Gerrit-Jan Blonk has been the manager), but the ALS patients themselves were not unified, so they did not have a voice in matters such as the which research was done and how subsidies were allocated.
Four years ago ALS patients Bernard Muller and Robbert Jan Stuit initiated a patient organization: ALS Patients Connected (APC) for patients and their families.
Both the ALS center and the ALS Foundation had to get used to the fact that there was now a third party that had to be taken into consideration.
After 4 years of hard work, ALS Patients Connected (APC) has become an equal partner to the ALS Center and the Dutch ALS foundation.
This four year lasting process, starting from its very beginning to becoming an equal partner, which this year resulted in a unique agreement of collaboration of the 3 parties, will be further clarified based upon the teething problems, points of discussion, conflicts, successes and learning curves.
We will also look into two of the successes of this collaboration: Project Virtual House and the Voluntary Caregivers app, the CALS-app.
-

-
- **Speaker** Nick Goldup
 - **Member Association** MND Association of England, Wales and Northern Ireland
 - **Title of Presentation** Improving MND Care Survey
 - **Theme** Stakeholder Engagement
 - **Abstract** Every two years, the MND Association of England, Wales and Northern Ireland endeavours to engage with its stakeholders through a detailed survey. This is the Improving MND Care Survey. This was last carried out in 2017 and the results have now been analysed and developed into infographics.

This survey has been combined now with a separate carers survey and asks both people with MND and their carers their opinions of both services provided by the MND Association and their perception of the quality of provision by statutory services, including both health and social care provision (funded separately in England and Wales, but funded jointly in Northern Ireland).

This presentation will explain how the survey was designed, the methodology, the numbers of returns demonstrating statistical viability and some of the key outcomes. It will also demonstrate a comparison between now and previous years and any key variations. It will also address the difficult question of asking pwMND/ALs and their carers their thoughts about their wishes relating to End of Life.

Finally, some of the key messages from the survey have been developed into infographics and these too will be demonstrated.

-
- **Speaker** Geet Rathi
 - **Member Association** 1870
 - **Title of Presentation** BLINK TO SPEAK – WORLD’S FIRST EYE LANGUAGE
 - **Theme** Looking to the Future
-

Abstract The worldwide prevalence of ALS is 6 per 100,000 of total population that is 4.5 lakh patients and they live with a paralyzed body and an alert mind. Every day patients struggle to communicate their basic needs and eventually they lose their ability to speak. The alternative methods of communication are very tedious, and the hi-tech assistive tools are unaffordable. The only movements possible to communicate till the very end, are the eye movements. So, we created the World's 1st eye language Blink to speak (Asha Ek hope foundation, Neurogen Brain & Spine Institute & TBWA)

Basic eye movements which can be done repeatedly and without fatigue were identified and turned into commands. Took inputs from PALS/CALS to understand their basic needs. A command made of eye movements permutation and combination was assigned to each phrase for easy communication. We made sure that the eye language is easy to use and covers all possible needs of a patient. Blink to speak eye language has 50 simple commands which are compiled in the Guidebook which is available free of cost.

It is available in English and translated 6 Indian local languages. It is also available online. This innovative creative idea won The Grand Prix Award of the Cannes lions & United Nations 2018.

-
- **Speaker** ADRIANA ODA
 - **Member Association** ABRELA
 - **Title of Presentation** A cause of all
 - **Theme** Partnerships and Collaborations
 - **Abstract** ABrELA – Brazilian Association of Amyotrophic Lateral Sclerosis is the first ALS Association in Brazil. For the last 20 years, ABrELA has been promoting activities in the benefit of ALS Community: PALS, CALS and professionals. These activities have been possible only because of the partnerships established throughout this time.

The lines of work developed by the association can be classified in four different areas: (1) Assistance to patients and closed relatives, with Programming for PALS/CALS e Stakeholder Engagement. (2) Teaching and training. (3) Research and investigation. (4) Advocacy.

For this purpose, partnerships had been built with public and private universities: training of professionals, integrated treatment in a specialized outpatient clinic in ALS (Social Work, Medicine, Physiotherapy, Speech Language Pathology, Nutrition, Occupational Therapy, Acupuncture and Psychology) and conducting and disseminating research in the area of Motor Neuron Disease. These researches have been taken to the congresses of related areas.

Partnership with other associations: awareness through contribution in a quarterly journal, elaboration and distribution of flyers and folders, walk for ALS, distribution of informative material for PALS, CALS and professionals, promotion of discussion in the Forum “ALS in the context of Rare Diseases in Brazil”, realized on 21th June, 2018, celebrating the International Day of ALS Awareness.

Partnership with private business: loans of equipment (non-invasive ventilation and Cough Assist®), donation of services in Right, Publicity, Marketing, Events Promotion and Management. Donation of resources for payment of employees and physical structure of ABrELA. Agreement with the judicial system in which the received part of donations are from convicts who are sentenced for social sanction.

Partnership with the Volunteer Group: volunteers promote several beneficent events during the year that help ABrELA on two important work lines: (1) to give visibility to the association and (2) to assist in fundraising, enabling the association to maintain its operation and fulfil its mission.

Partnership with professionals with expertise in the ALS/MND area, who disseminate ABrELA's purpose, through empowering courses, speeches in congress and symposia, elaboration of material with scientific technical background to publish in social media and printed media, meetings of awareness and support to PALS, CALS and relatives.

The bond and maintenance of all these partnerships are made through a compromise between the parties, so that the cause defended by ABrELA becomes a cause of all.

-
- **Speaker** Gleb Levitsky
 - **Member Association** Nina Levitskaya Russian Charity ALS Foundation
 - **Title of Presentation** Nina Levitskaya Russian Charity ALS Foundation- advances after the 10th anniversary
 - **Theme** Organizational Development
 - **Abstract** In 2016 our Foundation celebrated 10-year anniversary. However, 2016 was not a successful year. However, in 2017-2018 we met a new sponsor and managed to consult over 100 PALS and give NIPPV devices 10 times and communicator two times. Besides in 2017-2018 we made partnership with Chinese and Japanese colleagues in terms of conference in Beijing (we thank Alliance for the travel grant) and starting of supplementation of Russian PALS with edaravone, partially for Foundation money. We treated 15 patients and the drug helped in half of cases. We also try minocycline in PALS with elevated CRP and interleukine 6 (macrophagal inflammations), but preliminary results are inconclusive. Over 20 families received medications, wheelchairs, specialized beds and electronic lifters. In 2018 the Foundation was renamed after Nina Levitskaya, the famous soviet neurologist who died in 2015, mother of Gleb Levitsky. In 2017 we re-elected new President Savely Baschinsky who was presidium member since 2011 and whose publishing house donated NIPPV devices and communicator for foundation and printed copies of patient's information free of charge many times. However, our new sponsor left Russia in 2018 and we seek for new donations. The clinical base of the Foundation is Gleb Levitsky clinic which successfully works of the North of Moscow since 2013 and has a status of private ALS center.
-



"Science can be complex, but we manage the complexity by approaching problems as a team. On a team, you depend on people, and they depend on you. My son is learning the same lesson through sports."

Tony Romero, Ph.D., Associate Director, Medicinal Chemistry



As we celebrate our 20 year anniversary, we're shining a spotlight on our dedicated and passionate scientists. We are leaders in muscle biology research and are committed to developing new therapies for patients living with ALS.

Powered by Science



Cytokinetics