



## INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

**23<sup>rd</sup> Annual Meeting**  
Tuesday and Wednesday, 8-9 December 2015  
JW Marriott Grande Lakes, Orlando, FL, USA

### AGENDA

#### TUESDAY, 8 DECEMBER 2015

- |       |    |   |
|-------|----|---|
| 08:45 | 1  | Welcome & Introduction (30 min)   |
| 09:15 |    | <b>Annual General Meeting</b> (45 min)  |
| 10:00 | 2  | Opening Remarks from the General Manager (15 min)   |
| 10:15 |    | <b>Morning Refreshments</b> (30 min)  |
| 10:45 | 3  | Welcoming Our New Members (15 min)  |
| 11:00 |    | <b>Fundraising Strategies and Campaigns</b> (30 min)  |
|       | 4  | <i>Argentine Seawater Bucket Challenge</i><br>Pablo Aquino, The ALS Association of Argentina  |
|       | 5  | <i>Orchestrating Understanding: From Ice to Icons</i><br>Janet Nash, MND Australia  |
| 11:30 |    | <b>Allocation of Resources</b> (30 min)   |
|       | 6  | <i>Making the Right Investment Decisions: Work in Progress!</i><br>Sally Light, MND Association of England, Wales and N Ireland       |
|       | 7  | <i>How Does ABrELA Allocate Funding and Resources?</i><br>Tatiana Mesquita e Silva, ABrELA  |
| 12:00 |    | <b>Lunch</b> (60 min)   |
| 13:00 |    | <b>Challenges to Providing Services</b> (45 min)  |
|       | 8  | <i>Challenges Faced to Provide Services for ALS/MND Patients in India</i><br>Dr. Hemangi Sane, Asha Ek Hope Foundation                |
|       | 9  | <i>Social Media and Online Services In Building Multidisciplinary Team</i><br>Dr. Lev Brylev, Martha-Mary Medical Center "Miloserdie" |
|       | 10 | <i>Opportunities and Challenges</i><br>Wang Shunzhen, Beijing Oriental Rain ALS Care Center (BORACC)                                  |

13:45      **Services, Programmes and New Ideas to Support PALS/MND (90 min)**

11 *Virtual Support Groups*

Jennifer LaRegina, The ALS Association, Greater Philadelphia Chapter

12 *Supporting the Children of PALS*

Jodi O'Donnell-Ames, Hope Loves Company

13 *Caring for Caregivers*

Marcela Santos, ACELA

14 *Fleet of Equipment and ALS Centers*

Christine Tabuenca, ARSLA

15 *Care for PALS Action*

Bingcang Yan, Shaanxi ALS Association

16 *The Future of Communication for ALS/MND*

Aki Yuki, JALSA

15:15      **Refreshments (30 min)**

15:45      **Partnership, Mentorship and Collaboration (45 min)**

17 *The Partnership Programme*

Efrat Carmi, IsrALS and Sara Feldman, ALS Hope Foundation

18 *Baltic Bridge: Supporting Collaboration and Education*

Kathy Mitchell

19 *Relay of Love*

Kiki Qu, Taiwan MND Association

16:30      **Networking (30 min)**

18:30      **“Warm & Fuzzy” Dinner**

**WEDNESDAY, 9 DECEMBER 2015**

09:00      20 Introducing the Strategic Plan for 2016 and Beyond (30 min)

09:30      21 Workshop (60 min)

10:30      **Morning Refreshments (30 min)**

11:00      **Scientific Update (30 min)**

22 *Scientific Update*

Dr. Terry Heiman-Patterson

11:30      **City Swims: Amsterdam and Beyond (15 min)**

23 *City Swim Presentation*

Gorrit-Jan Blonk, ALS Foundation of the Netherlands

11:45      **Including PALS/MND (15 min)**

24 *Nothing About Us Without Us*

Gudjon Sigurdsson, MND Association of Iceland

- 12:00     **Invitation to Dublin 2016** (10 min)  
The Irish MND Association
- 12:10     ***Thank You & Close: Meeting Adjourns (Group Photo)***
- 12:30     Lunch (60 min)
- 14:00     **"Ask the Experts"**
- 19:00     Dinner hosted by The ALS Association

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# Cytokinetix

**Alliance Meeting Programme Committee**

Efrat Carmi, IsrALS, Israel  
Sara Feldman, The ALS Hope Foundation, USA  
Dr. Alper Kaya, ALS-MNH Dernegi, Turkey  
Jens Spanfelt, Muskelsvindfonden, Denmark

**Speaker:**

Pablo Aquino

**Member Association:**

Asociación ELA Argentina

**Title of Presentation:**

Argentine Seawater Bucket Challenge

**Theme:**

Fundraising Strategies and Campaigns

**Abstract:**

We completed the wonderful Ice Bucket Challenge 2014 campaign during the first months of the year, in the summer season of Argentina.

The purpose was to equip the Transportation Unit - acquired thanks to donations- for people with ALS and finance its annual operative cost.

In order to achieve such goal, we raised awareness and promoted thousands of bucket challenges along the beaches of the town of Pinamar, in the Atlantic Coast of the Province of Buenos Aires.

The success of the campaign produced thousands of bucket challenges by the sea shore.

With great attitude, participants gave donations, wore campaign t-shirts and threw sea water over their heads.

We raised enough money to equip the vehicle that is now at the service of ALS patients so they can move to their medical appointments, treatments and social activities.

**Speaker:**

Janet Nash

**Member Association:**

MND Australia

**Title of Presentation:**

Orchestrating Understanding: From Ice to Icons

**Theme:**

Fundraising Strategies and Campaigns

**Abstract:**

Despite the unprecedented boost in funds and the social media and celebrity frenzy of the 2014 ALS/MND Ice Bucket Challenge MND Associations and those living with MND recognised that many of the people who took part in the challenge did not fully understand the impact of ALS/MND. In late 2014 a woman diagnosed with MND approached MND Australia with a plan to increase understanding of ALS/MND in Australia and to raise funds for research. She brought together branding, market research and ad agencies, film makers and a major department store, all on a pro bono basis, to develop a unique branded awareness campaign. The campaign ran during May 2015 and despite widespread TV and radio coverage little was raised as a result of the campaign.

However, this person had touched the hearts of the ad agency! In July 2015 MND Australia was invited to meet with 'The Works' to talk through an idea for an awareness film. The idea involved aussie icons: singer Tim Minchin, the Sydney Symphony Orchestra and a Crowded House song.

Incredibly all agreed to be involved on a pro-bono basis with just a small investment from MND Australia to cover some production costs. The idea is to evoke the progressing paralysis and loss that people living with ALS/MND experience through the orchestra, the singer and the song.

This presentation will outline the development of the video and key messages to ensure an understanding of ALS/MND and the process of promotion and online platform development to ensure optimal fundraising opportunity via social media. The video is due for release in November providing the opportunity for us to present the video to the International Alliance members.

**Speaker:**

Sally Light

**Member Association:**

The MND Association of England, Wales and N Ireland

**Title of Presentation:**

Making the Right Investment Decisions: Work in Progress!

**Theme:**

Allocation of Resources

**Abstract:**

The MND Association is fortunate to be going through a period of income growth after a few difficult years. Even without the IBC money we saw income grow last year to the highest figure in our 36 year history. The vast majority of our income comes from voluntary donation and with income comes responsibility! In this presentation I would hope to provide an overview to our risk based approach to income budget setting, discuss how we are developing a more robust, business case approach to any significant additional investment requests and talk about how we identify our investment priorities based on our strategic plan. I would also like to share how we are looking to base more of our decisions on understanding the outcome and impact of what we do - to ensure that we do the things that most benefit people living with MND. And finally to discuss how we approached the IBC investment decisions and the role our members played in steering those decisions. The presentation will have a practical, rather than financial, content which I hope would be of interest to Associations who are also looking at how best to fulfill their financial stewardship responsibilities. I am conscious that English is not the first language of many members and would try to tailor the presentation accordingly.

**Speaker:**

Tatiana Mesquita e Silva

**Member Association:**

ABrELA (Brazilian ALS Association)

**Title of Presentation:**

How Does ABrELA Allocate Funding and Resources?

**Theme:**

Allocation of Resources

**Abstract:**

ABrELA (Brazilian ALS Association), has been a member of the International Alliance for more than 10 years. Our office is a space of about 10 square meters, we have four employees, and we can receive over 1000 calls per month. How is this possible, knowing that we are in a country with over 200 million citizens and 8,516,000 km<sup>2</sup>?

ABrELA has some strategies to get resources, they are: 5 fixed donors; events volunteer team; 2 rental properties; events in general and a national symposium annually.

In 2014, with the Ice Bucket Challenge, ABrELA not only got a huge influx of resources (USD\$ 85,000.00 in 3 months), but also got some loyalty donors for the cause who began to donate monthly.

For ABrELA to be able to stay for more than 15 years helping ALS patients, their families and caregivers and training health professionals, we have a lean physical structure, with three social workers and a secretariat, which give account of telephone calls by e-mail and in person people from all over Brazil (over 600 calls per month).

ABrELA has a governing body and a deliberative council of volunteers. Thus, we present the statistical patient care in 2015, showing what we do and how we do it.

**Speaker:**

Hemangi Sane

**Member Association:**

Asha Ek Hope Foundation (India)

**Title of Presentation:**

Challenges Faced to Provide Services for ALS/MND Patients in India

**Theme:**

Challenges to Providing Services

**Abstract:**

Asha Ek Hope is the first foundation for MND/ALS in India. Founded in 2011 by a physician (MD, NYMC, U.S.A.), who is a patient of ALS herself, and has been successfully battling the disease for the last 10 years. The foundation has a vision to support patients with ALS/MND, and to promote research that will help find a cure for the disease. The foundation has experienced a lot of hurdles since its conception because of various factors.

**Patient and community related:** The first and foremost challenge for the foundation is the lack of awareness about the disease in the community as well as among health professionals. The diagnosis is often late and the guidance offered is inadequate for patients to understand the nature and prognosis of the disease. The foundation was conceived to ease these difficulties for the patient, however getting access to the patients itself, is challenging. Even after getting in touch with the patients the next challenge is to bring the patients to the care facility or providing care for the patients at home. Various infrastructural, economical and social factors limit our efforts to provide care to the patients. It is difficult to train the patients with the use of various assistive devices and supporting equipments as the instructions are mainly in English which is not a native language in India. There are also difficulties like lack of electric supply, place and sanitization facilities for the usage and maintenance of these equipments. Families from the rural areas or the lower economic strata of the community find it difficult to devote time for the patients as their earning potential is limited. The grim fate of the disease adds to their apathy towards the patient. The patients also lack motivation to battle the disease in such situations.

**Medical and rehabilitative system related:** There isn't a national registry of these patients with the epidemiological data. Within medical fraternity there is lack of experience and interest in treating patients with ALS/MND due to rare occurrence, lack of exposure in the training hospitals and colleges. There are only a few experts in the field and therefore their services are difficult to avail or unaffordable for some patients. The infrastructure in very few hospitals is conducive for the multidisciplinary care of the patients. The only medicine for ALS/MND is rilutor and the process to get this medicine is tedious and time consuming.

**Funds related:** Being a young and the only foundation in India for MND/ALS the foundation is struggling with raising funds. Tax exemption and online payment access are some of the difficulties foundation has faced in the near past. As there is dearth of funds deciding on funds allocation is also challenging. We support research that has shown positive outcomes in some cases but for larger and more conclusive trials, the funds available are inadequate.

Asha Ek Hope Foundation has been battling these challenges for last 4 years and has now charted a long term goal and activities to overcome these.



**Speaker:**

Lev Brylev

**Member Association:**

Martha-Mary Medical Centre "Miloserdie"

**Title of Presentation:**

Social Media and Online Services in Building Multidisciplinary Team

**Theme:**

Challenges to Providing Services

**Abstract:**

Amyotrophic lateral sclerosis is a rare disease. In Moscow we have about 600 patients with ALS and only few specialists, who have experience in ALS. In Martha-Mary medical center we organized a charity project to provide a multidisciplinary home health care for ALS patients. We invited neurologists, pulmonologist, intensive care specialist, psychologist, palliative care specialist, physical therapists, social workers to join our team. Majority of these people work in our project part-time. To coordinate our activities and provide high-quality care timely we meet once per week and the rest of time team-members communicate via social networks and online services. Secret groups and personal messages gives us opportunity to involve all members in making decisions. We provide home health care for 110 patients in Moscow, and all of them have access to all kinds of specialists, who have experience in ALS, who communicate with each other. We believe, that this experience could be adapted and implemented in other countries

**Speaker:**

Wang Shunzhen

**Member Association:**

Beijing Oriental Rain ALS Care Center

**Title of Presentation:**

Opportunities and Challenges

**Theme:**

Challenges to Providing Services

**Abstract:****I. Opportunities**

- a. Ice Bucket Challenge: In this activity, the Center and the Chinese people gradually raised funds, obtaining financial support from all sides. Total: 1,000,000 RMB for poor families to provide free bipap and ventilator subsidies.
- b. The ALS Fund: On August 2014, the center in cooperation with the China Social Welfare Foundation established the ALS United Way fund.
- c. Join the International Alliance: We will establish more extensive international exchanges, hoping to work together with all countries and regions, to do our best to destroy ALS.

**II. Challenges**

- a. Weak Infrastructure: Although concerns and challenges are more visible because of the social effects of the ice bucket, and the center has been developing rapidly for two years, the region's infrastructure is weak.
- b. Publicity: Publicity is obsolete, with low attention, and it has large expenses but income is not obvious. Activity could not overstep "ice bucket challenge."

**III. Response and Development**

- a. Set Up Fundraising Platform & Build Donor Database: Efforts to expand the center's network and actively participate in online fundraising platform to create and fund public projects.
- b. Establishment of Volunteer Teams: Establishment a team of volunteers to assist with simple work.
- c. Establishment of BORACC Regional Sub-Station: The fundraising advantage ALS Fund has combined some organizations to develop Internet fundraising programs, starting from the local people. Form a joint force.
- d. Social Media Fundraising Platform & Interactive Activities: Publishing innovative activities through social media, raising ALS awareness in the mode of the ice bucket challenge, and social fundraising through a network platform to improve fundraising totals.

**Speaker:**

Jennifer LaRegina, RN, BSN

**Member Association:**

The ALS Association, Greater Philadelphia Chapter

**Title of Presentation:**

Virtual Support Groups: the Ins and Outs of Computer-Based Support Groups

**Theme:**

Services, Programmes and New Ideas to Support PALS/MND

**Abstract:**

The potential for stress and isolation among caregivers of persons living with ALS (PALS) is immense. Our goal was to address caregivers' needs for connection, resources and supports by reducing the logistic obstacles caregivers incur in order to attend a group in-person. To achieve this we are offering real-time audio-visual virtual groups via user-friendly, HIPAA compliant, accessible, and cost-free mainstream technology. These virtual groups provide caregivers with the opportunity to meet, share information and support each other. We currently have two active virtual caregiver support groups: one for general ALS caregivers, which has run monthly for 18 months, and one for caregivers of PALS on vents which began in June 2015. We will discuss our experience with various media options we have tried while considering HIPAA compliance. We will review differences and similarities in setting up and facilitating on-line groups on a variety of computer-based technologies including desktop, laptop and tablet applications, as well as the challenges and benefits of virtual support groups.

**Speaker:**

Jodi O'Donnell-Ames

**Member Association:**

Hope Loves Company

**Title of Presentation:**

Supporting the Children of PALS

**Theme:**

Services, Programmes and New Ideas to Support PALS/MND

**Abstract:**

Our presentation is a five-minute video which highlights Hope Loves Company®. HLC is the ONLY non-profit in the U.S. with the mission of supporting the children and grandchildren of ALS patients by providing free resources, camps and family fun days. HLC provides emotional and educational support to this unique group of caregivers through our various programs: Hugs of Hope care packages, free children's books, free family fun days and Camp HLC®. HLC's main event, Camp HLC® is a free weekend retreat which offers a safe place for children ages 8-21 and their ALS families to connect, have fun and learn valuable resources that will help campers handle the challenges of loving and losing a loved one to ALS.

Camp HLC® is for children who have or have had a parent or grandparent living with ALS. It is a fun three-day overnight retreat and an opportunity to learn team building exercises, to meet other children who are in the same situation and to feel supported and appreciated. Camp is provided free for our ALS families by HLC and sponsors. At Camp HLC® campers have the chance to partake in art therapy, meet with a friendly counselor, learn distressing mechanisms and to share their ALS experience in a comfortable, informal environment.

The HLC video that will be shown during our presentation in Orlando contains pictures and clips from our programs, mostly Camp HLC®.

There are currently several researchers investigating the effects of ALS on children. We feel that this research will help others to understand the impact that ALS has on our young caregivers and will fuel the need for an HLC outreach. It is our mission to expand HLC beyond the east coast of the U.S. and to implement more programs nationwide and perhaps, even worldwide one day. Thank you for your kind consideration.

For more information about HLC, please visit:

[www.hopelovescompany.com](http://www.hopelovescompany.com)

<https://www.facebook.com/HopeLovesCompany?ref=hl>

<https://www.youtube.com/watch?v=ZRZmG-oA85w>

**Speaker:**

Marcela Santos

**Member Association:**

ACELA

**Title of Presentation:**

Caring for Caregivers Program

**Theme:**

Services, Programmes and New Ideas to Support PALS/MND

**Abstract:**

We often think about helping and providing for the patient living with ALS, but we forget that caring for their caregivers is equally as important. Caregiving implies modifying a lifestyle, facing the pain of watching a loved one being physically limited day by day, experiencing a new way of communication, facing the fear of losing a loved one, acquiring new skills, making difficult decisions and finding a new meaning in life. All of the above, with an unconditional moral obligation filled with love for his/her family member living with ALS.

That's why, seeking for solutions, in 2005 we joined forces with the Nursing Department of the National University of Colombia, which offered a program for caregivers of patients with chronic diseases. Using similar parameters we created our very own program intended exclusively for caregivers of patients with ALS. Its aim is to reduce the burden of caregivers through the analysis of the experience of care, identifying their strengths and limitations and empowering them in care-giving.

The program is directed by an interdisciplinary team consisted of a nurse, a psychologist and ACELA's volunteers, whom have all experienced care giving for a family member with ALS. Within the topics covered in the sessions, there's life projection, coping, resilience, well-being, decision making, caregiving skills, communication, and relationship strengthening. Its has been widely accepted by the caregivers, specially because they appreciate the fact it's a space thought for them, where they can express their feelings openly with no room for judgment. We have also found that the caregivers well being influences directly on the well being of the patient, they have reported strengthening of their relationship, making it an easier and healthier one.

The main challenge we face is the lack of regular attendance because they don't have anyone else that can take care of the patient while they attend the sessions. To overcome this challenge, we decided to do the program on Saturdays and it has been a successful change, increasing the amount of attendees. We are proud to present this program and we invite our fellow associations of the International Alliance to think of programs where the rest of the people involved in a patient with ALS/MND's life are included.

**Speaker:**

Christine Tabuenca

**Member Association:**

ARSLA (France)

**Title of Presentation:**

Fleet of Equipment and ALS Centers

**Theme:**

Services, Programmes and New Ideas to Support PALS/MND

**Abstract:**

One the principal mission of ARSLA is the loan of material for patients, wherever in France.

Our fleet of equipment

Because ALS induces a loss of autonomy, our organization has set up a fleet of equipment. All of ARSLA's equipment is loaned free of charge by simple request. ARSLA has 18 equipment fleet in all of France for the needs of patients. At each stage of the progression of the disease, ARSLA has an appropriate equipment to help patients: toilet assistance, communication aid, assistance for the writing... Our fleet of equipment is very important because the cost of products for disabled people is too expensive for patients and the ALS evolves too quickly to invest on those. ARSLA helps people with its fleet of equipment because system of French social insurance not allows a good reimbursement of expenses.

Another important point of our organization is the access to care. That's why ARSLA has promoted the creation of 18 centers named "ALS centers" which are centers of specialized and multidisciplinary medical consultations. These centers cooperate with our non-profit organization to contribute to improving the patients quality of life. ALS centers and ARSLA organize time for meetings and discussions between caregivers/team of researchers/patients. ALS centers write technical datasheets and "tip sheets" for caregivers/team of researchers/patients.

"ALS centers"

These centers provide the patient with comprehensive care. In the same place, during the same visit, families have access to various specialists (neurologist, cardiologist, pulmonologist, psychologist) under the responsibility of one doctor referent or coordinator. Thanks to a better and quicker comprehensive care patients are best taken care and their daily way of life with disease is better too.

**Speaker:**

Bingcang Yan

**Member Association:**

Shaanxi ALS Association

**Title of Presentation:**

Care for ALS Patients Action

**Theme:**

Services, Programmes and New Ideas to Support PALS/MND

**Abstract:**

Shaanxi ALS Association has been set up for 20 months. We follow the tenet of "mutual care" and have established a platform for 253 patients in Shaanxi province of China to communicate information. We have organized volunteers and related nursing & medical personnel to do home visits. We held series of activities to present assistive devices, breathing machine and nutrition powder and supply appropriate subsidies to melt frozen heart.

**Speaker:**

Aki Yuki

**Member Association:**

JALSA

**Title of Presentation:**

The Future of Communication for ALS/MND

**Theme:**

Services, Programmes and New Ideas to Support PALS/MND

**Abstract:**

In JALSA, a new way of communication is gradually being introduced into the patients' lives. It is a robot with camera, microphone, speaker and motors, connected to PC and eye-tracking devices like Tobii. A camera is integrated into its head, motors are loaded on parts like necks and arms, and a patient can control all of them through the eye movement. The robot will tilt its head and see wherever you want to see, even if your real sight is fixed to the ceiling. The robot will move around its arms to convey simple gestures like "hi", or clapping hands. You can type what you want to say and let the robot voice it for you, too.

They have been introduced into individual patients' lives, and also they have been at work when JALSA held a general meeting. Four robots, each controlled by a JALSA member, had their place in the meeting instead of the patients who found it hard to attend the actual meeting. Finding cure for these cruel diseases is important, but at the same time, helping patients cope with their daily lives is equally important. These robots are experimented and developed to fit ALS/MND patients' daily communication needs.

Patients who have been using these robots have been giving positive feedbacks, some stating that they gave them the opportunity to see what's actually going around them visually, like their pet dogs running around the floor. Furthermore, family of these patients have also gave us the positive feedbacks saying that they felt like they were having an ordinary conversation because the robot nods, claps and moves around constantly. The project is still on going, and we'd love to share this new piece of technology into any ALS/MND related conference or meetings held around the world.



**Speaker:**

Efrat Carmi and Sara Feldman

**Member Association:**

IsrALS, ALS Hope Foundation

**Title of Presentation:**

The Partnership Programme

**Theme:**

Partnership, Mentorship and Collaboration

**Abstract:**

Background: The Partnership Program has been developed to support the objectives of the Alliance and to assist organizations in achieving a standard of good practice in the management of ALS/MND.

Objective: To provide information on the Partnership Program and discuss the role of the Alliance in expanding and supporting partnerships.

Program Description: The Partnership Program is made up of two parts, Mentorship and Partnership.

Mentorship: A program aiming to help new organizations to establish a solid structure to the benefit of the ALS community in their countries. Newly formed or forming organizations will be accompanied by an experienced mentoring team of the Alliance. A case manager, who is a well experienced figure in the ALS organizational world, and a team of professional mentors in different subject such as: research, patient care, awareness, education, fundraising, advocacy etc.

Partnership: This program is in place for organizations to share information or resources, form relationships, or collaborate on activities. In establishing these relationships it is essential for all parties to understand the other's development, social and economic background, and work together to identify opportunities to be pursued as part of the collaboration. The Alliance meetings bring together our members who network effectively during the meeting and collaborations are encouraged. In addition, the Alliance has the Needs and Offers program where members are asked to identify areas they need assistance with or assistance they can offer. Several recommendations for successful collaborations were made. The objectives of the collaboration should be identified, clearly stated and written down. This helps to establish the boundaries of the collaboration, to know when the collaborative effort on that project is completed and as an aid to evaluation.

Needs and Offers: The Needs and Offers program encourages members to both identify any 'needs' their organisations may have as well as to 'offer' their skills, programmes and resources. This sharing has led to the development of partnerships, outreach programmes and inter-organisational support.

Outcomes: There have been several successful projects to date. We will provide a brief overview of these stories as well as refer interested members to the website.

Recommendations: We would like to promote the Partnership and Mentorship program to the membership and answer any questions they may have.

**Speaker:**

Kathy Mitchell

**Member Association:**

Individual/Associate

**Title of Presentation:**

Baltic Bridge: Supporting Collaboration and Education

**Theme:**

Partnership, Mentorship and Collaboration

**Abstract:**

As a Professor of Nursing I have collaborated with ALS associations in Estonia and Russia to present education programs based on my professional knowledge and expertise. In the last five years, I have continued my communication via email and in person at the Alliance meetings. I was invited to the Latvian Association Motus Vita meeting in August 2015. These efforts will continue as our patients in these countries are in need of the Alliance outreach programs.

Financial support from the Alliance has made this collaboration possible. Partnerships are developed through mutual initiative and motivation to establish shared expertise, which will improve quality of life and care for people living with ALS/MND.

The Alliance continues to develop global collaboration with the sharing of knowledge and skills. We are truly united for the best care for all.

**Contact details:**

Kathleen Mitchell, R.N. B.N.

Professor (Retired), Algonquin College, Ottawa, Ontario, Canada

Email: mitchek@algonquincollege.com

**Speaker:**

Kiki Qu

**Member Association:**

Taiwan MND Association

**Title of Presentation:**

Relay of Love

**Theme:**

Partnership, Mentorship and Collaboration

**Abstract:**

The Taiwan MND Association organized the 2015 Asia-Pacific ALS/MND Conference on April 11 and 12, 2015, which attracted more than 440 participants from seven countries, including Australia, Belgium, China, Japan, Malaysia, Taiwan and U.S.

As the first regional ALS/MND meeting in Asia Pacific, the event got great support from the alliance members, Japan ALS Association (JALS), MND Australia, and ALS Liga Belgium. The one and a half day program had four sections:

1. **ALS/MND Stories:** telling the stories of people living with ALS/MND and their exploration of love and life values in adversities.
2. **Holistic Care Workshops:** sharing professional practice and experiences in serving and taking care of people with ALS/MND.
3. **Medical Forum:** discussing the latest advances in the international ALS/MND researches and drug experiments.
4. **Organization Operations:** exchanging ideas on service programs, fundraising strategies, volunteer recruitment, training and retaining from different organizations.

**Outcomes:**

During the meeting:

1. Created a platform for people with ALS/MND and their families to get support.
2. Increased the professional knowledge and convictions for medical and service professionals.
3. Provided opportunities for service groups to build connections and share experiences.
4. Drew hearts closer and made people with ALS/MND feel they are not alone through intimate interaction and talk during meeting break and banquet.

After the meeting:

1. Form a close relationship with ALS/MND organizations from China and Malaysia and provide consistent support.
2. Help two ALS organizations from China join our international alliance, Beijing Oriental Rain ALS Care Center (ORACC) and Shaanxi ALS Association. The MND Malaysia has submitted their membership application.
3. Build strong collaboration with ALS Liga Belgium to increase the public's awareness of ALS/MND and improve quality of care and service to people living with ALS/MND. The ALS Liga Belgium donated 14 nearly new, properly functioning and personalized power wheelchairs to Taiwan. The press release will be held on November 14, 2015, with the theme of "Relay of Love + Compassion".
4. The next Asia-Pacific ALS Conference is under planning. With the assistance of the Taiwan MND Association, it will be sponsored by the Beijing Oriental Rain ALS Care Center (ORACC) in May 2017.

**Speaker:**

Gorrit-Jan Blonk

**Member Association:**

ALS Foundation of the Netherlands

**Title of Presentation:**

Amsterdam City Swim: Worldwide Ambition

**Abstract:**

In 2012, the first Amsterdam City Swim was held in Amsterdam. The result was that the event raised 629,000 euro at ONE day. In that year also our Queen Maxima joined the swim. In 2013 the event raised 1.7 million and in 2014 almost 2.2 million. This year the event was held for the first time not only in Amsterdam (1.8 million) but also in New York City. That was the first international swim with almost 450 participants and nearly 500.000 dollar raised. The board of the Amsterdam City Swim is looking for the possibility to swim in more cities around the world besides Amsterdam en NY in 2016 and further on. The presentation will be about the years behind us but especially about the wish and the possibility to swim in more cities around the world. The money will stay in the country where the swim will take place and must go to research and care for ALS.

**Speaker:**

Gudjon Sigurdsson and Arnný Guðjónsdóttir

**Member Association:**

MND Association of Iceland

**Title of Presentation:**

Nothing About Us Without Us

**Theme:**

Including PALS/MND

**Abstract:**

We will talk about the importance of PALS in the whole work of every association. How important we find involving PALS in all our work. How our work is useless without PALS involved in every step we take. Not only to be used for fundraising, but being able to attend meetings like this. NOTHING ABOUT US WITHOUT US.



# Cytokinetics



**Proud Platinum Sponsor of**  
***23rd Annual Meeting of  
The International Alliance  
of ALS/MND Associations***