



## INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

21<sup>st</sup> Annual Meeting  
Tuesday and Wednesday, 3 and 4 December 2013  
Quasar Room, Atahotel Quark, Milan, Italy

### AGENDA

#### TUESDAY, 3 DECEMBER 2013

- 08:45      1 Welcome & Introduction (30 min)
- 09:15      **Annual General Meeting** (45 min)
- 10:00      2 In Memory of Jeffrey Deitch (15 min)
- 10:15      Morning Refreshments (30 min)
- 10:45      **Communication (Technology)** (90 minutes)
- 3 *The Kevin O'Donnell Independent Living Initiative*  
                         Sara Feldman, The ALS Hope Foundation
- 4 *Language is Hope, to Be Heard*  
                         Martin Burger, ALS Vereinigung.ch
- 5 *Communication Aids for ALS Patients: Some Initiatives of the French Association ARSLA*  
                         Yves Tronchon, ARSLA
- 6 *Assistive Technology Program for Israeli ALS Patients*  
                         Efrat Carmi, IsrALS
- 7 *Family Communication During the Disease Process*  
                         Carla Yolotl Flores Plancarte, FYADENMAC
- 8 *Communication Support as an Aspect of Palliative Care in Japan*  
                         Yumiko Kawaguchi, Japan ALS Association
- 12:15      **Burnout** (30 min)
- 9 *Keeping Staff Healthy*  
                         Rod Harris, MND Victoria
- 10 *Compassion Fatigue and Burnout Amongst Carers as Informal Caregivers*  
                         Steve Bell, MND Association of England, Wales and Northern Ireland
- 12:45      Lunch (60 min)
- 13:45      **Communication (Outreach)** (60 min)
- 11 *Examples of Video Movies to Reach Awareness for ALS and to Highlight Achieved Milestones*  
                         Mia Mahy, ALS Liga Belgium

- 12 *Stem Cells: Communication Between Myth and Reality*  
Christian Lunetta, AISLA Onlus
- 13 *Having a Good Website Isn't Enough: Communication Tactics to Meet the Needs of Both the Patient and the Organisation*  
Robert A. Goldstein, ALS Therapy Development Institute
- 14 *Information, Communication and the Spread of ALS in Argentina*  
Pablo Aquino and Dario Ryba, ALS Association of Argentina

14:45 **Fundraisers** (30 min)

- 15 *A Unique Fundraiser*  
AISLA Onlus
- 16 *UltraRun Marathon*  
Kiki Qu, Taiwan MND Association

15:15 Refreshments (30 min)

15:45 **Palliative Care** (45 min)

- 17 *One Love, One Heart – Let's Care Together*  
Antje Faatz, DGM
- 18 *Palliative Care Studies Review in Russia, 2010-13*  
Gleb Levitsky, Russian Charity ALS Foundation
- 19 *ALS Respiratory Decision Making*  
Dee Norris, The Forbes Norris Foundation

16:30 Free Time

18:30 "Warm & Fuzzy" Dinner

**WEDNESDAY, 4 DECEMBER 2013**

- 09:00 20 Overview of Strategic Plan 2012-15 and Report on 2013 Actions and Outcomes (30 min)
- 09:30 21 Workshop: Priorities & Working Groups for 2014 (60 min)
- 10:30 Morning Refreshments (30 min)
- 11:00 **Coping with the Diagnosis** (15 min)
- 22 *We Are With You When the Difficult Time Comes*  
Kiki Qu, Taiwan MND Association
- 11:15 **Sexuality** (15 min)
- 23 *Sexuality in ALS*  
Dr. Anna Marconi and Dr. Federica Fossati
- 11:30 24 *A Scientific Presentation with Non-Scientific Language* (30 min)  
Professor Adriano Chio
- 12:00 **Partnerships Update** (30 min)
- 25 *Reaching Out: Continuing to Develop Partnerships & Collaborations in Asia Pacific Region*

Carol Birks, MND Australia

26 *Nordic ALS/MND Meeting*

Gudjon Sigurdsson, MND Association of Iceland and Jens Spanfelt, Muskelsvindfonden

12:30 27 Brussels 2014 Presentation (10 min)

Meeting Adjourns

12:40 Photograph

12:50 Lunch (60 min)

14:30 **"Ask the Experts"**

16:30 **"Ask the Experts" Reception**

18:30 Dinner hosted by AISLA Onlus

**SPEAKER:** Sara Feldman

**MEMBER ORGANISATION:** ALS Hope Foundation (USA)

**TITLE OF PRESENTATION:** The Kevin O'Donnell Independent Living Initiative

**THEME:** Communication (Technology)

**ABSTRACT:**

Background:

Assistive technology can enhance the quality of life of person with ALS/MND by enabling them to remain independent in their ability to access their environment or communicate with others. New technology offers an alternate means for the individual to stay active and continue to participate in everyday activities. It is often challenging to know what appropriate technology is available to meet the individual's needs, and it is always challenging to find resources for funding it.

The Kevin O'Donnell Independent Living Initiative was developed to address these issues.

Objective:

To provide the education and technology needed to individuals with ALS who require assistive technology for communication or environmental access but encounter barriers to that access.

Program Description:

The Kevin O'Donnell Independent Living Initiative was established in memory of Kevin O'Donnell by his wife, Jodi O'Donnell-Ames. This initiative stresses the importance of accessing the environment and communicating with others. The program consists of three parts to assist the individual with ALS as they navigate through the maze of accessible technologies while dealing with their own ever-changing needs. The first step was to establish a library of currently available technology so individuals would have the ability to try equipment before making the decision to buy it, or to borrow it if purchasing a piece of high-tech, high-cost equipment was not possible. Second, a person who specializes in assistive technology would be part of the decision making team to help ensure the match between the person and the device was appropriate and optimal. Third, the initiative would encourage the use of cutting edge technologies to help motivate not only individuals with ALS, but also people on the design and engineering side.

The equipment in the library has been obtained through grants, gifts, and donations with an emphasis on communication devices. The equipment is maintained and catalogued by members of the clinic team, lead by the assistive technology professional, who also assist the individuals and families in the evaluations and decision making process. Support is given throughout, and people are able to keep and use the equipment as long as they need it. In addition, switches can be adapted by an engineering student to meet more individualized needs.

Recommendations:

As people with ALS experience a loss of motor skills, they may find that the use of assistive technology helps to restore their independence and allow them to function in their environment. This may include communication devices, computer access options, electronic aids to assist with daily living, and assistance with seating and mobility issues. Assistive technology solutions are as varied as each person's disease process and it is important to implement a device that best suits the individual needs. This initiative allows the ALS Hope Foundation to provide this equipment and support to individuals that require it. A similar initiative, based on local needs, can be implemented by other associations.

**MEMBER ORGANISATION:** ALS-Vereinigung.ch (Switzerland)

**TITLE OF PRESENTATION:** Language is Hope, To Be Heard

**THEME:** Communication (Technology)

**ABSTRACT:**

Our organization has the possibility to develop an APP for iPad/iPad Mini to improve the communication without installing a complex computer based communication system.

These are the functions of the app:

**12 Main Categories** with Items, according to the needs of the patient; they can be edited, and added, also with photos.

- Communication and Work
- Body (to detect pain)
- Positioning
- Treatment
- Well Being
- Nutrition
- Treatment Aids
- Medicine
- Clothes
- Urgent
- List of Products
- Treatment by external People

**Additional Functions Integrated**

- Alarm
- Start Internet, Facebook, Twitter
- Start E-Mail
- Choice of Music
- Details of the patient (PDF) e.g. Wills of the patient

**SPEAKER:** Yves Tronchon

**MEMBER ORGANISATION:** ARSLA (France)

**TITLE OF PRESENTATION:** Communication Aids for ALS Patients: Some Initiatives of the French Association ARSLA

**CORRESPONDING THEME:** Communication (Technology)

**ABSTRACT:**

Observing fifteen years ago that our Association had not appropriate communication tools to help ALS patients to communicate satisfactorily until the end of their lives, we have since, explored several possible ways to improve the situation.

Our presentation at the General Meeting of the International Alliance of ALS/MND Associations, coming December 3<sup>rd</sup> and 4<sup>th</sup> in Milano, will describe the various initiatives developed by our Association for several years in order to achieve the best possible that patients :

- . have access to information and to express themselves,
- . therefore can directly express their choices,
- . maintain a social life, have contacts with the outside world
- . maintain maximum independence
- ... until the end of their life whatsoever.

We propose at the Meeting of the Alliance to introduce various initiatives of the Association:

- 1 . conception and dissemination of information booklets on various existing materials of communication, especially among professionals, speech and occupational therapists,
- 2 . hiring an occupational therapist within the Association to meet and advise both patients, relatives and professionals,
- 3 . establishment of an immediate loan service and free equipment - especially communications equipments and environmental control – to all ALS patients according to their needs and in link with the professional who takes care of them (from boards of letters in plexiglass to sophisticated communication devices controled with eye movements ...)
- 4 . deposit material first in Paris, then more and more in France (15), closer to patients, in link particularly with ALS Centers all over the country,
5. working with companies to develop suitable materials for ALS patients  
( eg speech synthesis developed by a French little company called e-Rocca, at a good quality / price ratio)
- 6 . collaboration with government agencies to encourage repayment and pooling of such precious materials for ALS patients but expensive and sometimes unfortunately, used shortly,
- 7 . collaboration and loan equipment with structures of support to train staff in the use of some sophisticated devices in order to form patients, allow them trying the equipments, familiarize themselves  
... and save time ,
- 8 . Subscriptions to the public to finance new equipments and expand our equipments fleet, which now counts more than 1,500 units available for the 6000 patients with ALS in France over 500 communication devices.



Photo : eROCCA

**SPEAKER:** Efrat Carmi

**MEMBER ORGANISATION:** IsrALS – The Israel ALS Research Association

**TITLE OF PRESENTATION:** Assistive Technology Program for Israeli ALS Patients

**THEME:** Communication (Technology)

**ABSTRACT:**

Understanding that the gap between the cognition that stays intact and the ability to communicate that is rapidly deteriorating is the core of ALS, IsrALS has made a strategic decision.

Facing a reality where the needs of ALS patients for assistive technology are not met by the country, or any governmental or insurance entities, IsrALS realized that it our duty to make sure that no ALS patient left unheard and unable to communicate.

3 years ago we have decided that every ALS patient in Israel is entitled to get from us a full assistive communication assessment and support, throughout the entire disease.

We have initiated a collaboration with a group of occupational therapists from the Israeli Karten Institute that specializes in assistive technology assessments.

In the assistive technology program we provide:

- Set of 2 home visits:
  - **Initial assessment-** the patients get a home visit during which the OT examines their abilities, working environment and available equipment. They get a full report describing the current situation and recommendations of technological solutions.
  - **Follow up visit-** After the patients get the recommended equipment they get a follow up visit to make sure they fully use and enjoy the recommended solution
- The visits can be done either at the patient's home or work place.
- Each patient is eligible to get the set of 2 home visits any time his condition changes and he can't benefit from previous solutions any more.
- All visits are free to the patients and sponsored by IsrALS.
- IsrALS has a small pool of equipment and the patients need to borrow or purchase their own equipment.
- Recently we have initiated a complimentary follow up program by OT students. After the 2<sup>nd</sup> visit volunteering students come for additional 5 home visits and help the patients train and get used to working with the newly installed technological equipment.

**SPEAKER:** Carla Yolotl Flores Plancarte

**MEMBER ORGANISATION:** Familiares y amigos de Enfermos de la Neurona Motora A.C.  
(FYADENMAC – Mexico)

**TITLE OF PRESENTATION:** Family Communication During the Disease Process

**THEME:** Communication (Technology)

**ABSTRACT:**

Communication during the disease is of vital importance, since ALS patients, they face a challenge every day to express their feelings, emotions and needs, the health team as their families and caregivers. Generating anxiety and depression, problems that would limit the increase in their quality of life.

The presentation is focused to show the main points to create and maintain effective communication and the materials that can be counted regardless of socioeconomic level with you account for every family. In FYADENMAC are two main mechanisms to facilitate this communication through a book in person and through a software for computer use.

On the other hand it is also important to emphasize the importance of family communication to foster cohesion and cooperation resulting in an increase in the quality of family life and especially in patients with ALS.

Finally we offer some general recommendations assertive communication in the family and the health team.



**SPEAKER:** Yumiko Kawaguchi

**MEMBER ORGANISATION:** Japan ALS Association

**TITLE OF PRESENTATION:** Communication Support as an Aspect of Palliative Care in Japan

**THEME:** Communication (Technology) & Palliative Care

**ABSTRACT:**

The Japan ALS Association (JALSA) has been holding seminars since 1998 working to educate people with ALS/MND, caregivers, and healthcare providers throughout the country on essential palliative care.

Until 2012 these workshops held throughout Japan focused mainly on methods of suction and tube feeding conducted by helpers, but starting this year we have been working towards building up communication support systems on a national scale. This effort has been made because it is very important, even in cases of severe disability, to guarantee communication as a right of the patient.

As ALS progresses the techniques used to allow patients to communicate change. Proper care cannot be provided without knowledge of these various methods of assisting patients in expressing themselves. Ignorance of these forms of assistance is still common, however, and it is extremely important to educate not only the patient's family members and caregivers but also professionals working in this field.

As ALS progresses it becomes impossible for patients to express themselves freely, but other people must not stop making an effort to understand them. People with ALS are constantly facing death. Methods of understanding them right until the end stages of their illness are one of the most important means of alleviating their suffering.

In Japan many patients choose to stay alive for a long time through the use of mechanical ventilation, so it is not uncommon for a patient to become almost completely incapable of communication. In order to provide better palliative care for such patients, the development of Brain Machine Interfaces (BMIs), encouragement of research institutions, and empowerment of researchers working in this area are all being pursued.

BMIs are devices that allow characters (letters) patients picture in their minds to appear immediately on a computer screen. We would like to show video of this device in operation at the Alliance's annual meeting.

**SPEAKER:** Rodney Harris

**MEMBER ORGANISATION:** Individual Member, MND Victoria (Australia)

**TITLE OF PRESENTATION:** Keeping Staff Healthy

**THEME:** Burnout

**ABSTRACT:**

Keeping staff healthy is an occupational health responsibility. Ensuring staff are safe and well is a moral obligation. Having staff at work and working is a budget and financial necessity.

Just as any specialist worker needs to keep their tools in peak condition, ALS/MND Associations need to keep their staff and volunteers in good working order.

MND Victoria has 17 staff and a number of volunteers working directly with people living with ALS/MND. In 2012/13, this involved about 450 people with ALS/MND, 164 newly diagnosed and 135 deaths. It also involves working with over 650 other organisations supporting people with MND. In our current service environment, it also means not being able to get all the services and supports people need, on-going battles with government and funded agencies about service delivery, and recognition that our staff cannot work miracles in the current environment.

This presentation will describe the supports provided by MND Victoria for staff and volunteers working with people with MND, what they involve, and the financial cost. Observed impact in terms of sick leave or special leave will be highlighted.

**SPEAKER:** Steve Bell

**MEMBER ORGANISATION:** MND Association of England, Wales and N Ireland

**TITLE OF PRESENTATION:** Compassion Fatigue and Burnout Amongst Carers as Informal Caregivers

**THEME:** Burnout

**ABSTRACT:**

Whilst burnout and compassion fatigue is increasingly recognised amongst staff and health and social care professionals, often little thought is given to the effect of MND on those informal caregivers – the carers who care for the person with ALS/MND at home on a day to day basis.

This presentation will explore some of the strategic approaches taken by the MND Association to support the carers of people living with ALS/MND, separately to the cared for person.

The presentation will cover topics such as the need for carers support groups, but recognising the complexity in such groups between current carers and past carers; the need for planning for carers to be included in all our organisations plans and direction; the need to provide information specifically aimed at carers and the need to campaign for paid carers breaks – which carers often feel they cannot access or use due to the guilt in leaving the cared for person.

Finally, the presentation will highlight some of the key areas for action, following the implementation of the MND Association's carers' strategy and the progress made to date with its implementation.

**SPEAKER:** Mrs. Mia Mahy

**MEMBER ORGANISATION:** ALS Liga Belgium

**TITLE OF PRESENTATION:** Examples of Video Movies to Reach Awareness for ALS and to Highlight Achieved Milestones

**THEME:** Communication (Outreach)

**ABSTRACT:**

An introduction will be given to 3 video movies that were broadcasted in 2013 on behalf of the ALS Liga Belgium to reach general public awareness for ALS and to highlight milestones achieved by our organisation:

- 1) A spot broadcasted in the week 17-21 June 2013 on the Belgian public TV station VRT and the Belgian commercial TV station VTM at the occasion of World ALS-Day. The spot shows the devastating impact of ALS, not only on a Belgian pALS himself, but also on his family (partner, little daughter).
- 2) An announcement by Herman Van Rompuy, President of the European Council, that is continuously available at our website [www.ALSLIGA.be](http://www.ALSLIGA.be). The video calls for awareness for ALS and for specific support to our organisation.
- 3) A movie showing the official inauguration of Middelpunt ([www.middelpunt.com](http://www.middelpunt.com)), the ALS - Care Center at the Belgian coast, on World ALS-Day June 21 by His Royal Highness Prince Laurent of Belgium.

**SPEAKER:** Christian Lunetta

**MEMBER ORGANISATION:** AISLA Onlus (Italy)

**TITLE OF PRESENTATION:** Stem Cells: The Role of PALS Organization to Manage the Communication between Myth and Reality

**THEME:** Communication (Outreach)

**ABSTRACT:**

Unproven and unauthorized 'stem cell therapies' in ALS are not new. Since the diagnosis communication these topics represent the more frequent questions reported by PALS. Despite the fact of absence of any real evidence of efficacy, the majority of patients is willing to do any type of therapy as long as it includes stem cells. During the last year, in Italy a self-styled stem cell treatment is offered by a private non-medical organization in a public hospital, without any safety information and rationale, and violating current national laws and European regulations.

Despite several warnings from the scientific community to stop such treatment, the patient community has led many battles for the liberalization of stem cell therapies for compassionate use. Starting from this serious controversy between scientists and patients, AISLA has built a communication program aimed at improving understanding of the PALS that only rigorous science and strict regulation can ensure translation of science into effective therapies rather than into ineffective market products, and mark, at the same time, the sharp distinction between the fight for new therapies and the deceit of patients.

**SPEAKER:** Robert A. Goldstein

**MEMBER ORGANISATION:** ALS Therapy Development Institute

**TITLE OF PRESENTATION:** Having a Good Website is Not Enough; *Communication Tactics to meet the Needs of both the ALS Patient and the ALS Organization*

**THEME:** Communication (Outreach)

**ABSTRACT:**

ALS/MND is a progressive and fatal neurodegenerative disorder currently with no effective disease modifying treatments or cures. On average a person survives 2-5 years from diagnosis. However, since there are no definitive biomarkers of disease or other focused tools facilitating diagnosis, the process can take a year or more. People going through this process begin to *pull* information in from various sources, weighted heavily from online sources, about ALS/MND. From these resources, they learn about prognosis and the lack of effective intervention options. This presentation will frame a discussion on how organizations can and must go beyond traditional marketing and communication techniques in order to *push* information out to people living with a progressive disorder like ALS/MND. Real world examples will be provided from our Institute's communication platform. We will provide an example of email segmentation, user defined content generation and a working philosophy on how to engage with and provide patients and families the information they seek related to their disease.

**SPEAKER:** Pablo Aquino- Dario Ryba (Secretary and President of Asociacion ELA Argentina/ALS Association Argentina)

**MEMBER ORGANISATION:** Asociacion ELA Argentina / The ALS Association of Argentina

**TITLE OF PRESENTATION:** Information, Communication and Spread of ALS in Argentina: From a Virtual Community to an Action and Management Community.

**THEME:** Communication (Outreach)

**ABSTRACT:**

The role and function of the Community Manager. Institutional communication and personalized attention to those affected by ALS. The interaction of social networks to form synergy and sense of belonging. The presence of public figures to the massive spread of ALS through spots. Visibility strategies in the media. The inclusion of civil society organizations in Argentina and the world.

**SPEAKER:** Antje Faatz

**MEMBER ORGANISATION:** Deutsche Gesellschaft für Muskelkranke e.V. (DGM, Germany)

**TITLE OF PRESENTATION:** One love, one heart - let´s care together!

**THEME:** Palliative Care

**ABSTRACT:**

Palliative care is a growing sector in Germany's health system. Good regional structures have been developed during the last years. The concept of palliative care is suited to offer ALS patients a continuum of care from the day of diagnosis, it is not limited to a end-of-life-concept. Hospice movement/palliative care in ALS patient organizations share the same values and mission (dignity, autonomy, quality of life). But ALS care is challenging: a rare disease, progredient, diverse course of the disease, complex needs to be coordinated in short time. Palliative care services need information and education on the special needs of ALS patients. On the other hand ALS volunteers and peer counselors in patient organizations need education on palliative care and bereavement counselling as well as continuous support while being a part of the ALS care network. DEGM has started working together with the hospice movement and structures of palliative care on different levels. Cooperation between the sectors can be a win-win situation for both. We like to show some examples - activities on information, counselling, cooperation and education, some still delicate plans...



**SPEAKER:** Gleb Levitsky

**MEMBER ORGANISATION:** Russian Charity ALS Foundation

**TITLE OF PRESENTATION:** Palliative Care Studies Review in Russia in 2010-2013

**THEME:** Palliative Care

**ABSTRACT:**

In 2010-2013 we studied non-invasive ventilation, cognitive functions as well as control of emotional profile and sialorea in ALS.

Non-invasive ventilation (NIPPV) in S-mode studied in 37 PALS prolongs life in spinal ALS started when FVC in above 50% and in bulbar ALS started when FVC in above 65%. 80% of patients used IPAP 10 cm and EPAP 4 cm and 80% of patients increased pressures only once. We suggest that early tracheostomy in bulbar ALS may become an alternative life prolonging procedure with advantages over NIPPV.

Among 100 PALS 26% had cognitive change and 64% had emotional changes. Spectrum of emotional changes are depression, anxiety and mixed changes resembling signs and symptoms of shizoffective and obsessive compulsive disorders. The same signs and symptoms are often seen in PALS relatives. The drug cocktail that include cholinomimetic, atypic neuroleptic, antidepressant, hypnotic and gopantenic acid is the most adequate for cognitive and emotional control in PALS.

We also revealed cases of reversible cognitive changes in bulbar PALS in whom cholinergic drugs administered for sialorea (Atropine drops, Atrovent drops, Amythriptiline or Scopoderm plaster) are withdrawn. The most safe cholinergic drug for cognitive function was Buscopan 20 mg 3 times a day. There are two alternatives for cholinergics for sialorea in ALS – botulotoxine and irradiation of parotids. Dysport 250 U 1 time in 3-6 months combined with Amythriptiline 25-37.5 mg is ideal for bulbar PALS with moderate dysarthria and Dysport 500 U 1 time in 3-6 months or 6 Gr irradiation of parotids is ideal for anarthric bulbar PALS. There is a risk of anarthria acceleration in patients with moderate dysarthria with Dysport 500 U dose. Further studies are required to determine how often parotid irradiation have to be performed.

**SPEAKER:** Kiki Qu

**MEMBER ORGANISATION:** Taiwan Motor Neuron Disease Association

**TITLE OF PRESENTATION:** We Are With You – When the Difficult Time Comes

**THEME:** Coping with the Diagnosis

**ABSTRACT:**

It's very difficult for people and their family to accept the diagnosis of ALS/MND. As a service-oriented organization, we provide care and support with the human touch. In this presentation, the approaches we use to reduce their stress, frustration and uncertainty will be introduced.

Our organization has a close relationship with major hospitals around Taiwan. When physicians have newly diagnosed people with ALS/MND, they would refer them to our organization. For each new case, the immediate support is that we have a designated social worker to serve them directly: 1) evaluate the family's function, situation and financial status, and collect their special needs, if any; 2) provide disease-related information kit (including DVD and brochures for caregivers); and 3) explain what social benefits and resources they have and can use, e.g. psychological consulting, home-based PT, OT, speech & language therapy, and nutrition consulting.

In order to equip people with ALS/MND and their families with knowledge and confidence to live a challenging life in the long run, we provide continuous and holistic support in terms of information, psychology and finance. On the regular basis, we organize various activities, such as medical & education seminars, disease adaption groups, handmade workshop and summer retreat. During the process, it's very important to get support from fellow people with ALS/MND. We encourage peer support among families with ALS/MND.

Through face-to-face and personal way, we figure out what people with the diagnosis of ALS/MND need most and link up resources to help them find more calmness and less anxiety. At the same time, we let them know we are with them, stand by them and cheer for them to move forward.

**SPEAKER:** Monica Cattani

**MEMBER ORGANISATION:** AISLA Onlus (Italy)

**TITLE OF PRESENTATION:** Sexuality and ALS: Resource or Problem?

**THEME:** Sexuality

**ABSTRACT:**

There are limited studies on sexuality in ALS and most of them focused on the quality of sexual intercourse and not on the possible aberration of sexual activity. In our previous study (2012) regarding Aggressiveness, Sexuality and Obsessiveness on 10 patients with advanced ALS we found an increased sex drive but no alteration of sexual behavior. . We investigated these three domains with a structured interview using a specifically designed questionnaire which takes into account patients' communication limits and includes aspects related to sexuality (changes, desire, satisfaction, fixation). The PER-ALS questionnaire is currently We administered PER-ALS questionnaire not only to patients but also to their loved ones, to better understand how sexuality in ALS is not only a functional disease but affects the couple especially impairing body image. The aims of our study are to better understand how patients' sexual problems are linked to couple difficulties and how sexual relationship can affect couple quality of life also during the course of the illness. Since sexual interest remains active despite body limitation, efforts should be directed towards the couple in this respect and help to maintain proximity in order to facilitate communication. Psychological support and group therapy addressing specific sexual themes could help to direct preserved sexual drive to increase intimacy rather than generate further stress to the patient and caregiver.

**SPEAKER:** Kiki Qu

**MEMBER ORGANISATION:** Taiwan Motor Neuron Disease Association

**TITLE OF PRESENTATION:** Ultra-Run for ALS

**ABSTRACT:**

The International Tour de Taiwan Ultra-Marathon (ITTU), held on March 30 - April 12, 2013, collected donations of US\$57,000 for the Taiwan Motor Neuron Disease Association (TMNDA).

As we realize that there is a great similarity between the life experiences of ultra-runners and people with ALS, the organizer of the race, Chinese Taiwan Association of Ultrarunners (CTAU), and TMNDA, decide to launch a campaign, Ultra-run for ALS, to promote the global synergy between the ultra-marathon organizations and the ALS/MND associations.

In this presentation, I'll introduce how did ITTU help TMNDA, how to become part of the campaign and updates of current status.

**SPEAKER:** Carol Birks

**MEMBER ORGANISATION:** MND Australia

**TITLE OF PRESENTATION:** Reaching Out – Continuing to Develop Partnerships and Collaborations in the Asia Pacific Region

**ABSTRACT:**

Following a needs assessment to investigate the ALS/MND support available in countries in the Pacific and/or South East Asia region undertaken in 2011 MND Australia has continued to explore and make contact with key practitioners from countries in the region. At the Alliance meeting in 2012 we reported on the partnership that had developed with the China ALS committee during 2011/12.

Over the past 12 months, as part of the Alliance regional mentor and partnership initiative, MND Australia has worked to develop the Asia Pacific network group. Alliance member associations and health professionals from the region have confirmed their commitment and interest in being involved in collaborations in the region.

This presentation will provide an overview of engagement with key MND practitioners in Malaysia during 2013 and their plans to better support people living with ALS/MND in Malaysia.

As a well-established association and as a member of the International Alliance of ALS/MND Associations it is important that we reach out to maintain and to establish collaborations to enhance and promote sharing of information to promote the best possible care and support for people with ALS/MND in our region.