THE INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

INFORMATION UPDATE AUGUST 2013 ISSUE 34

A Message from the Interim Chairperson

Wendy Abrams, The Les Turner ALS Foundation

It's been a few months now since I have become your Interim Chairperson, and I must say that I miss Jeff greatly. I only hope that he would be proud of the way we are carrying on in his absence.

With the excellent help of Rachel, our Alliance Coordinator, and the Board of Directors, I feel we have made great progress and we will have excellent meetings in Milan.

I hope that each member association will find a way to send at least one representative to the meeting. I would love to see us have a record number of delegates present. The Alliance is your organisation, and in order for us to be successful, we need your help, input and guidance. That would also be a wonderful memorial to Jeff, so please join us.

The registrations for the meeting are posted, membership subscriptions for 2013/14 have been distributed, and opportunities to apply for a travel grant are also available. Please be mindful that you must be up-to-date in your membership dues to apply. I plan on seeing you in Milan!

Fondly, Wendy Abrams

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Register and Send Presentation Proposals for Milan 2013!

As you already know, the **21st Annual Alliance Meeting** will be held on 3 and 4 December 2013 in Milan, Italy. Our Alliance Meeting will be followed by **The Allied Professionals Forum** on 5 December and the **International Symposium** on 6-8 December.

Registration for all three meetings is now available. You will find more information, including instructions on how to register for the meetings and book a hotel, on our website: www.alsmndalliance.org/meetings.html.

You may have also seen the **Call For Presentations**, which was circulated by email in June. We invite delegates from our member associations to send presentation proposals by the deadline of **1 September 2013**.

You can download the Call for Presentations here: www.alsmndalliance.org/uploads/Call%20for%20Presentations-Alliance%20Meeting%202013.doc.

Please submit your proposal via email to coordinator@als-mnd.org.

Grant Opportunities

The Alliance is excited to encourage member associations to apply for an **Alliance Support Grant** this year.

The Alliance Support Grant has two purposes: 1) to help new and emerging member associations establish themselves; and 2) to assist member associations who might not otherwise be able to attend annual Alliance Meeting.

If your member association is concerned about the cost of attending the Alliance Meeting in Milan, especially if you have never been able to attend the Meetings before, we highly encourage you to apply for a Travel Grant!

Travel Grants will be awarded in the amount of **£1000 per association**, which can be used to cover travel and hotel expenses. In addition, registration fees for one representative to attend the Alliance Meeting and Allied Professionals Forum will be waived for grant recipients.

We cannot cover the cost of Symposium registration, but will offer recipients of the grant the opportunity to register for the Symposium at the early bird rate.

You can read more and download an application on our website: http://www.alsmndalliance.org/aboutus/support_grant.html. Please submit all completed applications to the

Coordinator via email. **The deadline is 1 September 2013.** We look forward to receiving your applications!

The Alliance's Global Day Campaign

We were excited and honored this year to introduce a new campaign for ALS/MND Global Awareness Day on 21 June 2013. We launched this program with help from the MNDA of England, Wales and Northern Ireland.

The Family of ALS/MND Charters asserts five basic rights that we believe should extend to people living with ALS/MND worldwide.

Since we launched the campaign, 11 associations spanning 4 continents have adopted the charter, and it has been translated into Italian, Spanish, Icelandic, and Turkish.

You can read the charter and learn more on our webpage: www.alsmndalliance.org/global-day-2013.html. If your association would like to translate or adopt this charter, please contact the Alliance Coordinator at coordinator@als-mnd.org so that we can include your association on our website.

Introducing Our New Member Associations!

We are happy to announce that the Directors reviewed membership applications and admitted two new associations to the Alliance at their latest Board Meeting on 1 July 2013.

The ALS Association of Argentina (Asociación ELA Argentina) was admitted as a **Full Member** of the Alliance. This association operates 9 chapters throughout Argentina with a headquarters in Buenos Aires. Their activities include running a multidisciplinary clinical center, providing community support for people with ALS/MND and their carers, and maintaining a loan bank of assistive technology and equipment. You can learn more by visiting their website: www.asociacionela.org.ar.

The Miquel Valls Foundation (Fundacio Miquel Valls) was admitted as an **Associate Member** of the Alliance. This association serves people with ALS/MND in Catalonia, Spain. Their activities include providing home visits, multidisciplinary medical care, and specialised equipment to people with ALS/MND in their unique region. You can learn more about the Miquel Valls Foundation by visiting their website: www.miquelvallsfoundation.org.

A Few Words from the Honorary Treasurer

Carol Birks, Honorary Treasurer

The Finance, Budget, Compliance and Administration Committee has met and engaged regularly during the last period. A budget for 2013/14 has been prepared and was approved by the Directors at the June Board Meeting. Rachel has focused on following up membership subscriptions for 2011/12 and 2012/13, which has resulted in a reduction to the expected deficit for the period. On behalf of the Board, I thank you for your patience during this process. Membership subscription fees for 2013/14 remain unchanged and notices for 2013/14 have now been distributed.

A full review of membership subscriptions, donations and sponsorship received has been undertaken to assist with the development of the budget and future financial planning. In addition, the Committee has reviewed the current situation of the restricted and designated funds. Restricted funds are reserved for contributions that are specifically named by the donor to support a specific program or purpose. Designated funds are funds that the Board designates for a particular purpose. The Board has approved allocation of £5000 of the Sanofi Aventis donation in restricted funds to support Alliance website development to improve access to information for Alliance members and people living with ALS/MND worldwide.

An Update from the Alliance Coordinator

Rachel Patterson, Alliance Coordinator

The time has flown by since I began my work for the Alliance in October of 2012. Since then, the Alliance has underdone many changes and faced many challenges—including the loss of our devoted Chairperson, Jeffrey Deitch.

Today, I am pleased to report that the Alliance is moving forward with confidence and dedication, honoring Jeff's memory and his commitment to building and strengthening this organisation.

In early June, I traveled to Europe to survey the site for the 2013 meetings in Milan and to liaise with the MNDA Conference Team. I must extend my heartfelt thanks to our Italian member association, AISLA, and to the MNDA team, who generously hosted me during my time abroad and who are working tirelessly to make sure that our upcoming meetings are a success. I am hopeful that the 21st annual meeting will be our best yet!

I also had the opportunity to collaborate with our friends at the MNDA to debut the **Family of ALS/MND Charters**. I am proud to be a part of an initiative that defends the rights of people with ALS/MND worldwide and thankful for the participation of so many of our member associations!

Most recently, I have sent out 2013 membership subscription invoices to coincide with the beginning of the new fiscal year. This year, we will collect and process payments in a timely fashion. **Please note that 2013 subscriptions are due 1 September.** Thank you for your support!

I look forward to seeing you again—or perhaps meeting you for the first time—in Milan!

Member Update: ALS Therapy Development Institute

Jessica Sullivan, ALS TDI

In honor of Global ALS/MND Awareness Day on 21 June, ALS TDI's online newsmagazine *ALS Today* has launched a new series of "postcards" to share stories of health professionals, scientists and patient advocates working to more effectively treat, care and support people with ALS around the globe. This year features updates from Sydney, Paris, Edinburgh and the Navajo city of Shiprock. View all the postcards at www.als.net/global.

Also in the spirit of Global ALS/MND awareness, ALS TDI hosted a webinar with Robert Bestow of MND Scotland to discuss a recent paper outlining knowledge gained in the last two decades of research into the causes of ALS and the current approaches at treatment being trialed in the lab and in the clinic. To view the recording, visit www.als.net/webinars.

Loftus Ranches and Hopunion in the US, purveyors of sustainable hops of the highest quality, have created Ales for ALS to support ALS TDI. Participating brewers nationwide were provided with a special blend of hops free of charge to create their own special beers, with a portion of sales to fund research at ALS TDI. Most brews debut this summer, so visit www.alesforals.com to find a participating brewery near you!

Member Update: Huge Step Forward in Australia

Rodney Harris, MND Australia

On 1 July 2013, the provision of support for people with disabilities, including people living with ALS/MND, took a giant step forward.

The Australian Government introduced

the national disability insurance scheme, called DisabilityCare Australia, which will fund the reasonable and necessary supports for all people with a disability under the age of 65, their families and carers. The scheme is funded by the Australian Government through a levy on personal income.

Until now, support for people with disabilities was based on eligibility and funding. If you were eligible, and if funds were available, you could receive services. This system funded service providers, who delivered a range of supports. This meant that people with disabilities had little or no control over their services.

MND Australia, the state Associations and their members worked hard through advocacy and influencing to represent the needs of people with ALS/MND in this new environment. Letter campaigns to politicians, Facebook and Twitter promotion, and meeting with politicians by all disability groups supported this huge step forward.

DisabilityCare Australia is a new way of funding individualised support for people with disability that involves more choice and control and a lifetime approach to a person's support needs. It creates an entitlement to access reasonable and necessary supports.

It will focus on early intervention, recognising that timely support can minimise the impact of a disability. It will provide assistance at the right time, rather than only once people reach crisis. Regular assessment and reassessment will ensure that funds meet the needs of the person, and be controlled by the person. Assessment will include discussion about individual goals and support needs, development of an individual plan that will help achievement of goals, include consideration of the supports needed to strengthen family and informal caring arrangements, and connection to mainstream services and community supports.

For people living with ALS/MND under the age of 65, DisabilityCare Australia will ensure that they can access the services that they need, when they need them, and exercise control and choice over those services.

DisabilityCare Australia is being introduced via launch sites around Australia, with people living with ALS/MND being engaged in sites in NSW and Victoria.

The scheme will extend to all people with disability under the age of 65 in Australia in 2018. Learn more: www.disabilitycareaustralia.gov.au/ or everyaustraliancounts.com.au/home/

Keep Up with the Alliance on Facebook and Twitter!

The Alliance is excited to be present on Facebook and Twitter. To get the latest news and updates, like our Facebook page www.facebook.com/theintlalliance and follow us on Twitter @alsmndalliance. Members are also invited to send updates and news to Rachel, the Alliance Coordinator, so that she can share them on our social media outlets.

Contribute to the Next Newsletter!

If you have news, information, ideas, or updates to share with Alliance members, please feel free to contact Rachel, the Alliance Coordinator, at coordinator@als-mnd.org. She would be happy to include these in our upcoming newsletter, which is scheduled to debut in October/November of 2013. Thank you!