

# THE INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

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## *A Message from the Interim Chairperson*

*Wendy Abrams, The Les Turner ALS Foundation*

It is with great honor that I serve the International Alliance at this time of great sadness. I accepted the position of Interim Chairperson in order to help the Directors during this time of uncertainty, and I look forward to working with all of you.

Jeff Deitch has been an advocate for the International Alliance for many years, and it is tragic that his leadership and hopes for the Alliance have been cut short. I know that he would want all of you to continue the fight against ALS/MND by growing your organizations and by raising awareness and fundraising so that we will be able to say someday that ALS/MND no longer exists. Keep Jeff in your prayers.

I know that our Board has been doing a lot of work since the meetings in Chicago and I want to assure you that they will continue to move forward to ensure the success of the Alliance for many years to come.

With that in mind, it has come to our attention that several members either didn't pay their annual membership fees last year, or were somehow not notified that their payment did not go through. Certainly, we want and need your memberships to meet our financial obligations going forward.

Rachel Patterson, our Alliance Coordinator, will be sending notices to all of you who haven't paid for 2012 in the hope that you will pay before the notices for 2013 go out. Full Members are required to have their annual dues paid in full in order to vote and to hold office—so please help us with these collections.



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The working committees are also looking at reviewing and revamping the membership structure, which we plan to have in place for 2014. Meanwhile, membership dues for 2013 will remain the same: Full Members .015% of annual revenue or £15, whichever is greater. Associate membership carries a flat fee of £50 and is designed for the smaller/newer associations who are just getting started, or for individuals who want to make a contribution to the Alliance. Associate members may not hold office (unless co-opted) or host the Alliance meetings.

Thank you all for your confidence in my ability to help the Alliance through these tough days. I look forward to renewing old acquaintances and making new ones.

Please let me know how I can best serve you.

Fondly,  
Wendy Abrams

## *An Update on Jeffrey Deitch's Health*

Many of you have read our email updates on Jeffrey Deitch's health. Recently, Jeff was discharged from the hospital into his father's home on hospice care. Sadly, his health has continued to deteriorate, and Jeff's doctors feel that he has run out of treatment options.

Jeff has battled his disease bravely; his determination and his accomplishments continue to inspire all of us.

Our thoughts and prayers are with Jeff and his family. If you would like to extend a personal message to Jeff or his loved ones during this difficult time, you may do so by contacting Rachel, the Alliance Coordinator, at [coordinator@als-mnd.org](mailto:coordinator@als-mnd.org).

## *Recap: Chicago 2012*

50 delegates from 18 countries attended the 20th Annual Meeting of the Alliance, hosted by the Les Turner ALS Foundation in Chicago, USA.

At the Annual General Meeting, **Jeffrey Deitch** (ALS Hope Foundation, USA) took over from Gudjon Sigurdsson (MND Society of Iceland) as Chairman of the Alliance, and **Carol Birks** (MND Australia) was appointed Honorary Treasurer. **Alper Kaya** (ALS-MNH Dernegi, Turkey), **Steven Bell** (MNDA, England), and **Efrat Carmi** (IsrALS, Israel) were welcomed as new Board members.

The meeting program was varied, covering topics such as 'Promoting research to your membership', 'Partnerships and Cooperation', and 'Supporting family members of people living with ALS/MND'.

We heard introductory presentations from three new Alliance member organizations from Russia, Latvia, and Peru. We also heard member updates from our organizations in Italy, Israel, and Belgium.

A session on the **Alliance Strategic Plan 2012 – 2015** provided an opportunity for the Alliance working groups to report to the membership on the work undertaken during 2012.

The membership offered recommendations, and the working groups clarified their action items and their agendas for the coming year. Chairman Jeff Deitch thanked the working groups and confirmed that the Alliance now had a clear direction for 2013.

You can read more about the events of our 2012 Meeting on Rob Goldstein's blog. Rob Goldstein is a representative from our associate member organization ALS TDI (USA): [Click here.](#)

You can also get information about our 2013 meeting on the Alliance website: [Click here.](#)

## ***Forbes Norris and Humanitarian Award Recipients***

At our Annual Meeting in Chicago, we also announced the winners of the 2012 Forbes Norris and Humanitarian Awards.

Congratulations to **Dr. Benjamin Brooks**, the recipient of the 2012 Forbes Norris Award. Dr. Brooks is a neurologist who has been caring for people with ALS for over 40 years.

Congratulations to **Mr. Gudjon Sigurdsson**, the recipient of the 2012 Humanitarian Award. Gudjon is the Chairman of the MND Society of Iceland, and he served as our Alliance Chairperson from 2008-12.

Read more about our recipients and their accomplishments on our website by [clicking here](#). You will also find nomination forms for the 2013 awards. We will begin collecting nominations on **May 1, 2013**, with a deadline of **October 1, 2013**.

## ***Introducing Our New Board Members***

In December of 2012, the Alliance welcomed 3 new Board Members: Steven Bell, Efrat Carmi, and Alper Kaya. Their photos and bios appear below. Please join us in welcoming our new Directors.



**Steven Bell** began working for the MND Association of England, Wales, and Northern Ireland in 2002. In 2009, he was appointed the Director of Care (North) for Northern England, Wales, and Northern Ireland.

Steve is based in Sheffield and is married with 3 sons, 1 daughter, and 3 grandchildren. He initially qualified as a Chartered Physiotherapist and specialized in working with adults with a learning disability. A further 9 years was spent as Chief Executive of a regionally based charity providing a full range of services for adults with Autism and Asperger's syndrome. He also qualified with an MBA from Sheffield Hallam University where he did a dissertation focused on the development of the "Contract Culture" within the charity sector.

Despite a busy and demanding work schedule, Steve still manages to continue as an active volunteer with his local scout group, where he has been Treasurer for the last 9 years. Steve has an eclectic range of personal interests outside work including fine wine, rock music and Rugby League.



**Efrat Carmi** has been with the Israel ALS Association (IsrALS) since 2007. In 2009, she was appointed CEO.

Efrat was born and raised in Jerusalem. She now lives in a small town in the northern part of the country and is operating from Haifa. Efrat has been leading IsrALS to promote ALS research in Israel and to develop and implement support programs to benefit people with ALS and their families.

Efrat got her B.A. degree in Psychology from Tel Aviv University in Israel and her M.B.A. degree from the University of Central Florida in the USA. She spent 9 years working as a regional manager in a Human Resources company in Israel and 8 years running a family business in the US. She is married and has 3 children, 2 boys and a girl.

Efrat is a great believer in sharing information and collaborating in and outside of Israel, understanding that a joint force can achieve bigger and better goals than separate individuals acting on their own.



**Dr. Alper Kaya** was born in 1961 and graduated from primary, secondary, and high schools in Izmir, Turkey.

In 1984, he graduated from the Medical School at Dokuz Eylul University. He worked for 4 years as a medical doctor and general practitioner throughout Turkey before earning the title of Specialist in Ophthalmology from Cukurova University in 1993. From 1994 to 2004, he worked as an Ophthalmologist in Uria at Izmir State Hospital.

In 1990, Alper was diagnosed with motor neurone disease. In 2004, he was hospitalized with acute respiratory failure and pneumonia and was discharged with a tracheostomy and ventilator support.

Alper retired in 2007. He has been living with ALS for over 20 years. He has developed his own virtual keyboard program on his computer in collaboration with a friend who lives in Germany. He continues to type with the help of OnScreenKeys virtual keyboard. Alper has not yet lost his ability to speak or eat.

Before his diagnosis, Alper played classical and electric guitar extremely well. He has worked with bands such as Dream Explorer and Group Alloy, as well as some New Folk groups.

Alper was married to Elcin in 1987. Together, they have a daughter, Ece, born in 1991. She is now a third-year student at Ege University studying Psychology.

## **Update from the Alliance Coordinator**

*Rachel Patterson, Alliance Coordinator*

I have been hard at work since taking on my position in October of 2012.

It was very rewarding for me to attend the 2012 Alliance Meeting in Chicago and to see how important the Alliance is in the lives of people with ALS/MND worldwide. Thanks to all who welcomed me in Chicago and who helped me along the way as we organized that meeting.

Since returning home from Chicago, I have turned my focus to straightening things out in the Alliance office and preparing for next year's meeting in Milan, Italy. I plan to travel to Europe in June to meet with our representatives at the MNDA and AISLA and to preview the venues for our 2013 event.

Additionally, I have been working closely with the Directors to update our membership and promotional materials and to make important revisions to our [website](#). Please, if you are an Alliance Representative, visit the [Directory](#) to make sure that the information listed for your organization is up-to-date. If you would like to make corrections or updates, please email me at [coordinator@als-mnd.org](mailto:coordinator@als-mnd.org).

I have also been updating our subscription materials, sending out invoices, and collecting fees. If you feel you may owe subscription fees or if you're not sure about the status of your member organization, please get in touch.

Feel free to contact me any time if you have any questions or concerns. As always, I am here to serve you!

## **A Message from the Honorary Treasurer**

*Carol Birks, MND Australia*

At the board meeting in Chicago, a **Finance, Budget, Compliance, and Administration Committee** was formed – see below. I look forward to working with this Committee and the Board to develop a financial strategy that will support us as we progress the work of the Alliance.

We cannot continue carrying out our mission without the subscription fees that help support our programs. Subscription notices for the current year (2012-2013) have recently been re-sent. If you have not received the invoice for your organization, please contact me right away.

## **Board Committees and Working Groups**

*Progressing the Strategic Plan 2011-14*

### **1 Budget, Finance, Compliance and Administration**

Carol Birks (Treasurer), Bob Bestow, Steve Bell

Assist the Board in the effective discharge of its responsibilities for financial management and in developing and supporting the role and function of the Alliance Coordinator.

### **2 Membership**

Evy Reviere, Ching-Piao Tsai, and Jane Gilbert

Evaluate new member applications and make recommendations to the board.

### **3 Support Grant Panel**

Teresa Salas Campos, Evy Reviere, and Bob Bestow



Evaluate Alliance Support Grant requests and make recommendations to the board.

#### **4 Annual Meeting Program** Efrat Carmi, Jens Spanfelt, and Alper Kaya

Design the Annual meeting program, call for abstracts, review abstracts, finalise program.

#### **5 Nominating** Carol Birks and Jeff Deitch

Identify new Board members and make recommendations to the Board.

During 2012, the four Working Groups established following the 2011 meeting critically analysed the Alliance in their identified area and developed recommendations.

A session in Chicago was devoted to reporting on these recommendations and discussing their merits. The recommendations are:

##### **1. Review our current operational structure and recommend changes needed to carry out our mission**

##### **2. Develop and enhance membership, partnerships and programs**

- Review membership criteria and subscription fees
- Improve support and information for new members
- Enhance and support partnership program
- Review and update documentation related to partnership program.
- Review the Alliance Support Grant Program
- Review program development for Alliance Meeting and enhance communication and engagement

- More effectively manage the Forbes Norris and Humanitarian Awards

##### **3. To facilitate the exchange of information on ALS/MND care, education, and research**

- Redevelop the website and online library
- Enhance engagement with Alliance members between Annual Meetings

##### **4. To build a sustainable operating/funding model for the Alliance**

- APF and Annual Alliance meeting to run at a profit every time
- Global Day initiative for Alliance - "the international fight against ALS/MND"

### **Global ALS/MND Day 2013**

The Alliance has recently become a part of a campaign to improve quality of life, dignity, and respect for people living with ALS/MND and their caregivers.

Originally undertaken by the MNDA of England, Wales, and Northern Ireland, this campaign is called **The Family-Tree of National ALS/MND Charters**. It will launch on **21 June 2013**, Global ALS/MND Awareness Day.

The goal of the campaign is to encourage as many organizations and countries as possible to adopt a Charter that asserts the rights of people living with ALS/MND. The Alliance Coordinator sent an email about this campaign to members of the Alliance which included a copy of the Charter and a media pack.

If your organization would like to participate in our Global ALS/MND Day festivities by adopting the Charter and you need more information, please contact Rachel, the Alliance Coordinator, at [coordinator@als-](mailto:coordinator@als-)

[mnd.org](http://mnd.org) or Raj Johal of the MND Association at [raj.johal@als-mnd.org](mailto:raj.johal@als-mnd.org).

We are happy to help and want everyone to have a chance to stand up for patients' rights in 2013!

## *Contribute to the Summer 2013 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](mailto:coordinator@als-mnd.org). She would be happy to include these in our upcoming newsletter, which will debut in June/July of 2013. Thank you!

### **United In The Worldwide Fight Against ALS/MND**

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