

## MNDcare Latest News December 2011

December focus:

- MND Aware now available on MNDcare website
- Overview of ALS/MND Symposium

### MND Aware now on-line

**MND Aware** –online training for service providers developed by MND NSW was launched on November 15 and has now been uploaded to the MNDcare website. This comprehensive educational package includes an [introductory module](#) and sections on [symptom management](#) and [wellbeing and support needs](#). It is easily accessible, flexible and can be used on an ‘as needs’ basis.

Poster and oral presentations were given at the recent ALS/MND Symposium and Allied Professionals Forum (respectively).

### 22nd International ALS/MND Symposium, Nov 30–Dec 2

Around 650 delegates attended the Symposium in Sydney this year including many prominent international scientific and clinical researchers.

The exchange of ideas and networking opportunities provided by this stimulating international forum engenders collaboration between scientists and care providers around the world.

#### [Headlines from the final day of the Symposium:](#)

*“By pulling together the different strands of MND research, this three-day conference enables delegates to reflect on the current MND research landscape and to look at how in partnership they can explore and develop the next exciting stages of Research”*

‘Dip into’ the atmosphere of this exciting event as [Dr Bryan Traynor](#) and [Dr Robert Browser](#) provide a quick overview on youtube.

For more detail of papers presented visit the blogs of the organisers of the International Symposium - the MND Association of England, Wales and Northern Ireland- [here](#)

### Allied Professionals Forum – November 29

Over 250 health professionals attended this forum from Australia and overseas. Themes of the Forum were wide ranging and included Diaphragmatic Pacing, the iPad as a tool for communication, nutrition, end of life issues and self-care and education tools for service providers. All presentations from the APF can be viewed in a streaming library at

<http://mnda.eventstreaming.tv/> - password **sydney** (all lower case) until the end of January 2012.

### Ask the Experts - November 28

This meeting provided the opportunity for people living with MND and their families to pose questions to a panel of international experts on ALS/MND. An exciting initiative this year was to stream the session online. Statistics show that people in 24



countries watched the session live online. It continues to be available for viewing at the streaming library -

<http://mnda.eventstreaming.tv/> - password **sydney** (all lower case) until the end of January 2012

This year's Symposium coincided with significant developments in scientific research. In the closing session Brian Traynor reported on the International Chromosome 9 Consortium eureka moment in discovering the holy grail of ALS/MND research - the discovery of C9orf72. He cautioned however that the time from a gene discovery to effective and safe gene therapy can take many years. Kevin Talbot went on to say that as more genes that influence MND are discovered understanding the complete genetic architecture of MND becomes a realistic goal. In his closing remarks he stated that evidence of benefit and international outreach is the key to improving access to ALS/MND evidence based care worldwide.

More details on recent research and links to APF and Ask the Experts sessions post January will be provided in our next newsletter in **February 2012**.

In the meantime we wish you a peaceful and happy Festive Season and thank you for your ongoing interest in and commitment to '*making a difference*' for people living with ALS/MND.