

## Alternative and unproven therapies and people diagnosed with MND

### POSITION STATEMENT

#### Background:

MND Associations often receive calls and e-mails from people regarding treatments being offered both here and overseas that claim to treat or cure MND. Often, these treatments are promoted on websites that feature in internet search results when people search for information about MND. It is very difficult for people living with MND and their families, desperate for effective treatments and a cure, to sort fact from fiction, and paid advertising from good quality health information.

Developments in stem cell research in particular, are still considered to be experimental, and with the range of claims being made every day about new cures, it's not surprising people are confused. There are many 'success' stories related to a range of unproven, alternative therapies and unproven stem cells therapies posted on the internet. Unfortunately there are just as many stories where these therapies have not been successful or where the improvement is for a very short time only. This highlights the need for properly conducted research trials to assess the effectiveness of any therapy offered.

**At present there is no evidence to prove that stem cell 'treatments' improve outcomes for people with MND and they can, in fact, be harmful.**

Resources currently available to assist people to make informed decisions about alternative and unproven treatments include:

- International ALS/MND Alliance **Statement on Alternative and Unproven Treatments and the MND Australia Research Policy**
- **The Australian Stem Cell Handbook** this handbook, updated in 2013, has been created to help people to understand the status of stem cell research and treatments in Australia and overseas.
- **The National Health and Medical Research Council (NHMRC)** have two resources on stem cell treatments. These resources provide medical practitioners and patients with a quick guide to stem cell treatments and the risks involved in undergoing unproven treatments.
- The **MND Australia website** provides latest research updates and information.
- **ALS Untangled** investigates alternative and off-label MND treatments

#### MND Australia believes:

Trusted information about current research and alternative and unproven treatments is vital to assist people to make informed decisions regarding any treatments being offered.

Treatments for any health condition can be:

- **beneficial or**
- **have no effect or**
- **cause harm through side-effects, adverse events or life-shortening effects.**

Any intervention must have been proven to be safe and to improve outcomes before it is made available outside of a clinical trial

**MND Australia calls for:**

- Doctors, neurologists, MND association and governments to support the development and provision of trusted and up to date information to assist people living with MND to make informed decisions
- The resources currently available to assist people decide about any claims being made about treatments or cures for MND to be updated regularly and promoted and disseminated widely
- Improved regulation of the increasing number of unproven experimental therapies and stem cell treatments being offered in Australia and overseas
- Research to be adequately funded to discover the causes, effective treatments, better care and ultimately a cure
- Access for Australians living with MND to properly conducted clinical trials.

*On behalf of the MND Australia board and state MND Associations*



**Signed: David Ali (President)**

**Dated: 26 June 2014**