



AMNDR Update for members

About the Australian MND Registry (AMNDR)

AMNDR has been collecting information on patterns of disease and interventions used in treating patients with motor neurone disease since inception in 2004. It is a way for people diagnosed with MND in Australia to actively contribute to research.

The goals of the registry are to improve patient care through continuous evaluation of patient management and associated outcomes and to form significant scientific research collaborations with organisations and individuals to further the understanding of MND.

Most people who wish to be involved in AMNDR are registered by neurologists associated with the MND multidisciplinary clinics and centres in Victoria, New South Wales, Queensland, Western Australia and South Australia which are all registered with AMNDR as clinical sites. Registrations can, however, be made by individual neurologists who will first need to contact Assoc. Professor Paul Talman the President of AMNDR on (03) 52267375 or pault@barwonhealth.org.au to receive the relevant forms, information and login details. The neurologist will also need to seek ethics approval from the hospital that he or she is affiliated with. They can then register with AMNDR as a clinical site and register their patients with MND who would like to contribute to AMNDR. Following registration the neurologist will need to complete online questionnaires with the person with MND at follow-up visits. Each person is allocated a unique ID number on registration and all information gathered is de-identified.

Some neurologists do not see many patients with MND and may not wish to register as a clinical site. If this is the case and you would like to be involved with AMNDR then you may like to get a referral to see a neurologist at the MND Clinic or centre in your state.

If you are not registered with AMNDR and would like to contribute to this valuable research please talk to your neurologist. If you have registered but have since moved and been referred to another neurologist please make sure he or she knows that you are registered so that they can continue to provide updates on your condition to AMNDR.

Latest News

Over 1200 people with MND have registered with AMNDR and at least 10 major centres from around Australia have been contributing information on a regular basis on behalf of people with motor neurone disease. Analysis of the data commenced in the second half of 2011 with the intention of creating a publication looking at factors that positively improve survival, clinical phenotypes and health service requirements. Funding has also been obtained for a formal audit of the AMNDR data which will be conducted in 2011. The collection of data relies heavily on the goodwill of a number of clinical research nurses and their consultant neurologists. This information will be a valuable resource for researchers into the future. In 2011 two new research collaborations using the AMNDR data have been initiated, one is looking at clinical phenotypes and cerebrospinal fluid, whilst the other is looking at the effect of non-invasive ventilation in MND.

The AMNDR Steering committee has been able to secure funding to run the database for at least another 5 years. It remains one of only a few active MND registries world-wide and this is a testament to people with MND and their carers, along with the dedicated staff around Australia that keep the registry running.

If you would like more information on AMNDR please talk to your state MND association or visit the AMNDR or MND Australia websites: www.amndr.org www.mndaust.asn.au

Carol Birks, MND Australia