



AMNDR Update for members

About the Australian MND Registry

The Australian Motor Neurone Disease Registry (AMNDR) was established in 2004 to collect data about people diagnosed with MND in Australia. It is a way for people diagnosed with MND in Australia to actively contribute to research.

AMNDR is a clinical database that provides a means to facilitate the collection and analysis of MND patient data such as demographics, site of onset, diagnosis data, treatment type, changes in functional capacity, complications related to disease progression and the impact of new treatments and interventions for MND. 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

Recruitment continues and to date 1067 people have been registered. There have been 418 registrants from NSW, 361 from Victoria, 202 from Queensland, 59 from WA, 34 from South Australia, 4 from Act and 1 from the Northern Territory. The steering committee meets at least annually and consists of neurologists from most states and MND Australia. The steering committee is currently looking into how to increase registrations overall and in Tasmania in particular. The registry has already provided a lot of valuable information on phenotypes (the different types of MND), region of onset, age and gender distributions and survival associated with the different phenotypes. The steering committee is currently developing papers on end-of-life issues and the clinical phenotypes of MND. Together these papers could provide clinical information for a national "model of care". The registry is now able to produce quarterly updates on registrations and information gathered which will be available on the AMNDR and MND Australia websites for members to access.

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

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