



International Alliance of ALS/MND Associations

The International Alliance and its role in ALS/MND Research

From the beginning the Alliance has always been focused on information gathering and dissemination as it relates to improving the lives of those who live with ALS/MND throughout the world. This objective is outlined explicitly in both the Memorandum and Articles of Association which have governed the Alliance since its inception and is the essence of the Mission Statement. Much of the material published or circulated by the Alliance focuses on the disease management and care strategies and standards which have been found to have been effective or helpful in some parts of the world and which could be utilised in others. Given that the nature of the member associations, which our membership criteria explicitly outline, is primarily that of care advice and delivery enabling bodies this is almost inevitable. However, at the time of the formulation of our guiding documentation it was recognised that several of our members would also be active in the arena of promoting, funding and guiding scientific research into ALS/MND.

In formulating the various objectives of the International Alliance to be included in the Memorandum it was determined that, in order to attract and encourage like-minded potential member associations, these should be sufficiently wide ranging to encompass all the activities of individual members even though many of them would not be carrying out all of these activities. One of these key activities is scientific research into ALS/MND itself. Scientific research is a very expensive activity to get involved in, especially if the member association is funding such projects. Clinical research and its related topics tend to be much less expensive to fund and positive results can be disseminated and put to use much more quickly.

In order to encompass both of these aspects of research activity the objectives of the Alliance include a commitment to promote and disseminate any results of research activities, without being specific in either the scientific arena or the clinical arena. This is spelt out in clause 4.7 in the Memorandum of Association, as originally published in 1999 and updated in 2006;

" promote, encourage, carry out or commission research, surveys, studies or other work, publishing the useful results;"

This is the only mention of research anywhere in either the Memorandum or the Articles of Association. There is no specific reference or mention of research in either field or of funding, either by way of awarding grants or by fundraising. In fact, to date although the Alliance has sought and published work in a variety of the disease management arenas it has not actually committed or expended any funds. It could be argued that the creation of the Allied Healthcare Professionals Forum component of the annual meeting falls into the area of funded research since many presenters at this event use this as an opportunity to publish and publicise specific clinical research activities that they have either completed or have ongoing

as works in progress. In this respect it resembles the activities and sessions of the regular scientific and medical research meetings such as the Annual International Symposium on ALS/MND.

To summarise, as it is presently constituted the International Alliance both recognises and encourages research but has no constitutional mandate to either fund or to fundraise for any such activities on its own behalf, except indirectly via the activities of the member associations.

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