

MOTOR NEURONE DISEASE ASSOCIATION HEALTHCARE RESEARCH GRANTS

TERMS & CONDITIONS

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All our Terms and Conditions are extremely important but we would ask you to pay particular attention to conditions 1-1.5 Funding arrangements; 10.1-10.4 Activation of Grant 11.1-11.3 Changes of Terms of Award 15.1-15.2 Reports; 17.1-17.10 Publications, Presentations, Acknowledgements and Publicity

MOTOR NEURONE DISEASE ASSOCIATION HEALTHCARE RESEARCH GRANTS

TERMS & CONDITIONS

All communication concerning grant applications and administration should be addressed to Natasha Rowe, Research Grants Co-ordinator, MND Association, 10-15 Notre Dame Mews, Northampton, NN1 2BG (natasha.rowe@mndassociation.org)

1 FUNDING ARRANGEMENTS

- 1.1 Projects are time limited. When the project is approved, the initial sum awarded by the Board of Trustees of the Motor Neurone Disease Association (herein after the Association) will be for the first year only, with funding in future years dependent on availability of funds. Approval of funding for later years is also subject to receipt from the grantee of all progress reports requested by the Association, whether as written documents of submissions through online systems, eg Researchfish. Written reports will be subject to review by the Association's Healthcare Research Advisory Panel (HRAP).
- 1.2 If the grantee under-spends in any year, the Association can, at its discretion, give approval for the balance to be carried into the following year. Expenditure beyond the end date will only be permitted if authorised by the Association in advance. Requests must be made by submitting a *Grant Amendment Application Form*, at least eight weeks prior to the original completion date (see grant condition 11.2).
- 1.3 Grants are available for the salaries of full-time or part-time workers, travel expenses (where necessary as an integral part of the project), consumables and equipment as specified in the grant offer. It is assumed that the usual office equipment, facilities and materials are available in the institution in which the work is undertaken.
- 1.4 The Association will not meet indirect or overhead costs of the institution such as general travel, finance services, staff facilities, staff development, public relations, publication costs, general institutional libraries, routine secretarial work, personnel services, stationery or contribution to general departmental costs. In exceptional circumstances some of these costs may be covered within a grant providing they have been included at the time of application, are of direct relevance to the project and are fully justified.
- 1.5 Conference attendance: upon presentation of invoices, the Association will fund up to £2000 of the cost of relevant conference attendance (travel and registration fees only) during the life of the project. The figure of £2000 must be included in the breakdown of costs on the original application. The attending researcher (who may not necessarily be the grant holder) is encouraged to present their work at these meetings (please refer to condition 17).
- 1.6 Overseas applicants must apply for funding in British pounds sterling; the Association must be invoiced in sterling and payments will be made in sterling.

- 1.7 Claims for reimbursement of actual project costs must be made quarterly in arrears through the research institution. All invoices must be accompanied with full details of amounts being claimed, ie employment costs and detailed breakdown of consumables, together with copy invoices for amounts of £1000 or over.

Payment of instalments at the end of each year and at the end of the project is conditional on receipt and approval of reports (see condition 1.1 and 15.1 and our Payment and Reporting Guidelines).

Final claims must be received within three months of the project's completion date. If this is not possible the Association must be notified and reasons given, otherwise it may not be possible for such invoices to be honoured.

- 1.8 **Funding from other sources:** financial support for clearly defined aspects of a project from separate funding sources is permitted under Association grants. Such supplementary funding must be disclosed at the time of research grant application or at the time such funding is received.

2 EQUIPMENT

- 2.1 Equipment purchased with Association funds within the terms of the grant must not be modified or removed from the grantee's institution without the Association's permission (unless the equipment is being utilised by patients participating in a clinical study). Should the principal investigator move to another institution during the tenure of the award, the Association reserves the right that the equipment be transferred with him/her following negotiation.
- 2.2 Items costing £2000 or more (inclusive of VAT) must be offered back to the Association at the end of the project for re-allocation, if appropriate. If no alternative use can be identified, the Association will offer the equipment to the original grantee.

3 ETHICAL CONSIDERATIONS

- 3.1 It is the responsibility of the grantee to make due application for ethical committee approval that may be required for all or part of the planned research. This should ideally be in place at the time of applying for funding.
- 3.2. Approval must be received and copies provided to the Association prior to the grant commencing. If any changes to the project require revisions to the ethical approval, the Association must be kept informed.

4 PERSONAL DIRECTION OF THE PROJECT

- 4.1 It is expected that the grant holder will be actively engaged in directing the project. Continued use of Association funds during a prolonged absence of the grantee requires written Association agreement to continue the research under the direction of another qualified investigator, ideally obtained prior to the absence. The grantee or the Head of Department must submit a *Grant Amendment Application Form* to the Research Grants Manager with an explanation of the situation, providing details of the arrangements for conducting the research during their absence (see grant condition 11.2).

5 RECRUITMENT AND EMPLOYMENT OF STAFF

- 5.1 The host institution is required to notify the Association of all new and replacement staff appointed to the project who were not identified on the original grant application (see grant condition 11.2).
- 5.2 The Association does not act as employer and, therefore, in all cases where financial support is provided for the employment of staff, the host institution undertakes to issue a contract of employment in accordance with the provisions of the Employment Act 1996 and any other relevant Act relating to the conditions of employment.
- 5.3 The Association will not be responsible for claims under statute or common law, nor will they indemnify the host institution against a claim for compensation or against any claims for which the institution may be liable as an employer or otherwise.

6 STAFF MANAGEMENT RESPONSIBILITY

The host institution must accept full responsibility for:

- 6.1 The management, monitoring and control for all those staff (permanent, temporary and students) employed or involved in any research funded as a result of an Association grant;
- 6.2 The management, monitoring and control of all research work funded as a result of an Association grant. This includes the requirements in the guidelines set down by: Control of Substances Hazardous to Health (COSHH), the Advisory Committee on Dangerous Pathogens (ACDP), the Advisory Committee on Genetic modification (ACGM), research on human embryos and the Health and Safety at Work Act (and non UK equivalents) plus any other regulatory requirements as may apply from time to time.

7 TERMINATION OF EMPLOYMENT

- 7.1 If the tenure of the appointment of staff recruited to work on the grant supported project continues beyond the period of the grant, the host institution will be solely responsible for all costs beyond the period of the grant. The Association accepts no liability for contracts and costs extending beyond the defined grant period.

8 SHORT TERM CONTRACTS AND REDUNDANCY

- 8.1 The Association expects that the host institution will have a policy with regard to employees with short term contracts that is in compliance with the European Union Fixed term work directive. The Association will not meet any claims for unfair or constructive dismissal and will only consider requests for additional costs to meet claims for statutory redundancy equivalent payments that occur as a direct result of the cessation of the grant (this could be at the end of its normal term or as a result of its earlier termination). Consideration will be limited to the period of service rendered by the grant supported employee during the period of the grant only.
- 8.2 Where members of staff have been under contract to the host institution prior to the activation of the Association grant, the Association will not reimburse costs attributed to any prior commitment. This includes any redundancy payments due for service prior to the grant period.

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- 8.3 The contract of employment offered must not extend beyond the termination of the grant (unless the host institution wishes to extend the contract at its own expense).

9 MATERNITY AND OTHER LONG TERM LEAVE

- 9.1 The host institution will meet the cost of any long term leave, other than holiday, and will ensure that all annual leave entitlement is be taken within the grant period. Long term leave may include maternity, paternity or long term sick leave.
- 9.2 Maternity or paternity leave is the responsibility of the host institution employing staff undertaking an Association project. Leave will be provided according to the host institution's local terms and conditions of employment. The costs of such leave are the responsibility of the host institution and are not provided for by the Association.
- 9.3 If an Association funded employee is due to take any planned long term leave, the grant holder should inform the Association of the date in advance. This will enable discussion to decide whether the grant should be suspended for the period of absence until full time employment can be resumed (see grant condition 11.2). If unplanned long term leave occurs, the grant holder or the Head of Department should contact the Association as soon as possible to discuss the situation with the Research Grants Manager.

10 ACTIVATION OF GRANT

- 10.1 Grants are activated on receipt of a signed grant activation form. If, for any reason, the start date of the project is delayed after the form has been returned, the Association must be informed at once, a *Grant Amendment Application Form* completed and a new start date agreed (see grant condition 11.2). If necessary a revised grant activation form will need to be completed and returned.
- 10.2 If the project does not start within six months of the original agreed start date, the Association may withdraw the grant offer. The grantee will have to reapply for funding in a future grants round, in competition with other applicants at the time.
- 10.3 Ethical Approval: The Association must receive evidence that ethical approval (if required) is in place prior to the project starting. Payment of invoices will be delayed until evidence has been provided. It is the responsibility of the grantee to make due application for ethical approval and this should ideally be in place at the time of applying for funding.

11 CHANGE OF TERMS OF AWARD

- 11.1 Reallocation of funds from one expense heading to another, as detailed in the grant award letter, requires written permission from the Association.
- 11.2 Grantees will be required to complete a *Grant Amendment Application Form* detailing any and all proposed changes to the project. Applications must be submitted (where possible) at least eight weeks prior to the changes taking place. The Association must be kept informed at all times of any changes to the original grant.

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- 11.3 Any request for major changes in the terms of a grant, eg for additional staff or equipment, must be made in the form of a new and separate grant application, which will be considered by the HRAP panel.

12 CHANGES TO CONDITIONS OF GRANT

- 12.1 The Association reserves the right to change the [Terms and Conditions of Healthcare Grants](#) at any time. If this occurs during the lifetime of a grant, the revised Terms and Conditions may be applied in place of those issued at the time of the original award. Grantees will be informed by email if this is the case. The most recent version of this document should always be accessible from the Associations website.

13 EARLY TERMINATION OF AN AWARD

- 13.1 The Association reserves the right to terminate a grant at any time. Circumstances which might lead to termination include:
- Any breach in the terms and conditions under which the award was made.
 - If the project has not started within six months of the agreed start date.
 - The work is diverging markedly from the original approved project. Grant holders must inform the Association and provide details, immediately they are aware of a change of direction (see grant condition 11.2). There may, however, be circumstances in which the change is acceptable on scientific grounds.
 - Failure to submit adequate progress reports, or failure to submit information through an online reporting tool (eg Researchfish) when requested.
 - Any serious and unresolvable problems identified by a site visit.
 - Work has stopped on the grant, or the principal investigator has ceased to be actively involved in the project. The Association must be informed immediately if the situation arises (see grant condition 11.2).

The Association will endeavour to give 60 days prior notice before termination of an award.

- 13.2 If an award is terminated, the Association will meet costs properly and necessarily incurred under the award up to the termination date. However, payments will not, in aggregate, exceed the amount of the grant remaining to be paid at the time of termination of the award.
- 13.3 In the event of work being discontinued by the host institution, written notification must be sent to the Association, together with a report on the work carried out to date, setting out reasons for the termination. In this event a final claim is to be submitted within the terms of the award and the usual time limits.

14 EXTENSION TO GRANTS

- 14.1 It is the responsibility of the principal investigator to apply for further support before the end of the award period, if this is required. Applications for an extension of support may be considered in isolation or as a new application in competition with other applications at the time of applying (see grant condition 11.2).

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- 14.2 Adequate time, at least eight weeks, should be allowed for an extension application to be processed and the Association accepts no responsibility for any costs incurred due to the failure of a grantee to make such an application in good time.

15 REPORTING ON GRANTS

- 15.1 The grantee must submit to the Association:

- 15.1.1 **Annual progress reports:** these are due within four weeks of the anniversary of the start date (see grant condition 1.1), using the Association annual report form, with figures and diagrams where necessary. A short summary in language intelligible to the lay reader (see grant condition 15.1.3) should be included for possible use in Association publications. Annual reports will be reviewed the HRAP.
- 15.1.2 **Interim reports:** if the project is funded through the Association major donor scheme, or advised by the HRAP that careful monitoring is required, the grantee will be required to provide brief six monthly reports of no more than two pages.
- 15.1.3 **Final report:** these are due within six weeks of the end of the project using the Association's final report form. A detailed final report covering the whole project will be substituted for the annual report. A lay summary should also be provided in language intelligible to the non-scientist reader. Grantees must avoid the use of jargon and technical language (eg mutation, phenotype, transgenic and aggregate to name but a few) and should pitch the lay summary at the level of a health science feature in a broadsheet newspaper. This may be used in Association publications.
- 15.1.4 The final instalment of the grant will only be paid after receipt of the final report and its approval by the Healthcare Research Advisory Panel. Payment may be delayed further if reports are not submitted on time and/or if clarification is required.
- 15.2 **Online systems for grant outcomes reporting:** if requested, the grantee must also upload all relevant information via any online reporting tool used by the Association, for example Researchfish. This form of reporting may be requested by the Association in addition to the requirement for annual and final reports. The grantee may be asked to continue such online submissions up to five years after the grant has ended.
- 15.3 **Feedback to people with MND and/or Carers** – all grantees are encouraged to provide regular information on their research to be used in Association publications or circulated to interested supporters. Where volunteers are involved in research, grantees are required to provide regular feedback to the participants and the Association, in addition to annual reports and publications.

16 SITE VISITS AND PROGRESS MEETINGS

- 16.1 The officers of the Association reserve the right to visit the grantee's institution during the period of the project to discuss progress and welcome invitations to do so.
- 16.2 The grantee may be asked to attend six monthly progress meetings to discuss progress with Association representatives and donors. These may be arranged in conjunction with site visits.

17 PUBLICATIONS, PRESENTATIONS, ACKNOWLEDGMENTS AND PUBLICITY

- 17.1 Grantees are expected to seek publication of findings in refereed journals during and as soon as possible after conclusion of the project (subject to condition 18). The Association and the grantee jointly undertake to notify each other before published reference is made to the findings of the project and to reach agreement on the form of publication wherever possible.
- 17.2 Grantees must inform the Association's press office and the Research Grants Team immediately when results from Association funded research are accepted for publication or presentation. The grantee must provide the Association with reprints, photocopies or electronic copies of the final version of any such publications.
- 17.3 **Open Access Policy**
All peer reviewed papers directly arising from the grant must be made available through open access. These research papers should be available within the Europe PubMed Central (Europe PMC) repository as soon as possible but within six months of publication of the paper. Please see our [website](#) for more details.
- 17.4 **Posters: costs and accessibility**
If Association funded research is accepted for presentation as a poster, the costs of poster production may be claimed as part of the consumables budget (to a maximum of £100 per grant). The poster must acknowledge the MND Association as a source of funding and should include the Association's logo. Ideally a copy of the poster should be made publically available on an appropriate website after presentation, eg f1000.com/posters. The Research Grants Team should be provided with a link to the website location or an electronic copy of the poster.
- 17.5 To ensure the long-term sustainability of income for research and to reflect and maintain the Association's reputation for funding research of the highest scientific excellence and of greatest relevance to MND, all opportunities to promote the Association must be pursued. The grantee and the host institution are obliged to co-operate with the charity over any publicity or fundraising activity arising from research funded by the Association. Where it is the main funder of the research, the Association reserves the right to lead on publicity.
- 17.6 Grantees and the host institution must notify the Association's press office at least five working days in advance of any publicity arising from research wholly or co-funded by an Association grant, using communications@mndassociation.org. Any press release or other material including reference to Association funded results must be approved by our communications office before it is released to the media.
- 17.7 In any oral, written report or poster presentation relating to Association funded research, the author must acknowledge our support and display our logo. All references to Association funded work placed on websites, electronic bulletin boards and similar must state clearly that the work is funded by the 'Motor Neurone Disease Association' and ideally a link should be included to the charity's website: www.mndassociation.org.
- 17.8 Grantees must ensure that the Association's support is acknowledged in all publications, presentations and similar. It is essential for grantees to acknowledge that their research has been supported wholly or in part by the Association, either in the text or in a footnote. The grant reference must also be included.

17.9 When speaking publicly and to representatives of the media about the Association funded research, grantees and researchers should ensure they make it clear to the media and others that they should be presented as a 'Motor Neurone Disease Association funded scientist'. Please note that researchers should consult our communications office before speaking to the media, communications@mndassociation.org

17.10 There is a subtle but important difference between speaking as a 'Motor Neurone Disease Association funded scientist' and acting as a spokesperson for the Association. Representatives of the media may not always be aware of this difference. Researchers who speak to the media must ensure that their personal views are not misrepresented as being attributable to the MND Association. Our communications office can provide support in dealing with the media.

18 PATENTS, COPYRIGHTS AND OTHER INTELLECTUAL PROPERTY

18.1 If ideas, processes or products of potential commercial value are generated as a result of the project, the grantee must obtain the written consent of the Association before taking any steps to exploit the results commercially. The grantee accepts that the Association may require a share of financial gain in return for its consent. This restriction shall continue to bind the parties notwithstanding any termination of the grant. For further detail, please see Appendix 1 – Intellectual property rights and commercial activities.

19 MND ASSOCIATION MEETINGS

19.1 Grantees are asked to make themselves or other appropriate research team members available to report on the project at Association meetings, fundraising events and occasionally at other times by invitation.

19.2 There may be occasions where the grantee will be asked to present their work at scientific and or healthcare professionals' meetings.

19.3 When speaking and presenting at Association events, grantees or other appropriate research team members are expected to make it clear in the presentation their funding connection with the Association.

20 MND ASSOCIATION CASE STUDIES

20.1 Grantees are asked to make themselves available as case studies reflecting the work of the Association for the charity's wide-ranging communications and fundraising activities.

When a project involves the use of item 21, 22 below, applicants must provide evidence with their application of approval by the relevant ethical or regulatory body. If such approval is pending at the time of application, activation of the grant will be conditional of provision of relevant documentation to the Association.

Non-UK institutions should comply with UK regulations, also referring to their national regulations as required. If these are significantly different to regulations in the UK, the grantee must comply with the higher standards, seeking advice from Association staff as necessary.

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21 REMOVAL/USE OF HUMAN TISSUE

- 21.1 Grantees should note that the Association expects that any procedures undertaken during the course of their projects involving the removal of human tissue at post-mortem examination will be carried out in accordance with the Human Tissue Act 2004, the guidance issued by the Department of Health/Local Health Authority and that [issued by the MRC for their grant-holders](#).
- 21.2 In addition, when research projects involve the use of human tissue/blood samples grantees will be asked to state, in their final report, what happened to any remaining samples at the end of the project, ie whether they were disposed of, or if they will be used in another project.
Please refer to the [Human Tissue Act 2004: Code of Practice 5 – The disposal of human tissue – Sept 2009](#)
- 21.3 **Samples from the UK MND Collections** (formally the UK MND DNA Bank)
If the research involves the use of samples (eg DNA, cells) from the [UK MND Collections](#) the grantee will be required to apply for this separately.
The grant may not be activated unless the access to samples and/or data has been formally approved, so the application for access should be made in advance of the grant start date.
The grantee must agree to abide by the Terms and Conditions for sample use.
- 21.4 Within the annual reports, details will be required of the samples used and the outcomes of the research. This is in addition to reporting required as part of the terms and conditions of access to samples.
- 21.5 **Embryonic stem cell research**
Approval of research on human embryos is only granted when it is viewed as necessary under strictly defined guidelines, outlined in the [Human Fertilisation and Embryology Act 2008](#). Where work is subject to these guidelines; applications for all licences and certificates required under the act must be made directly to the [Human Fertilisation and Embryology Authority](#) through the host institution's normal channels.
- Any use of cell lines derived originally from embryonic stem cells must be specified in the funding application. If the use of such cell lines was not part of the original workplan, the grantee must seek permission from the Association before such work is undertaken. Completion of the Grant Amendment Application Form may be required and the advice of the HRAP may be sought.

22 ANIMALS

- 22.1 Grantees are expected wherever possible to adopt procedures and techniques which avoid the use of animals. Where this is not possible, investigators are required to show that they will use only the minimum number of animals consistent with achieving a valid result in any experiment and that experimental protocols have been designed to minimise pain, suffering and distress. This condition applies to the use of animals for which a licence is not required.

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Advice can be obtained from the [UK National Centre for the Replacement, Refinement and Reduction of Animals in Research](http://www.nc3rs.org.uk/page.asp?id=871). Please refer to their page titled: [Responsibility in the use of animals in bioscience research: Expectations of the major research councils and funding bodies](http://www.nc3rs.org.uk/page.asp?id=871)
<http://www.nc3rs.org.uk/page.asp?id=871>.

- 22.2 Where the work is subject to regulation by the Animals (Scientific Procedures) Act 1986, the provisions of the act must be observed with respect to both the spirit and letter of the law. Applications for all licences and certificates required under the act must be made to the Home Office direct through the host institution's normal channels. It is recommended that these channels include review by an animal care and use committee.
- 22.3 Any grant award made by the Association will be on the condition that no work which is controlled by the act will start until the necessary licences and certificates have been obtained.
- 22.4 **Using animals to test potential drugs and other treatments**
Where the research involves preclinical drug testing in animal models of ALS/MND researchers are expected to follow the guidelines (see below) resulting from two meetings: the European ALS/MND group held a meeting in 2006 and the guidelines were published in 2007¹. A second international conference to improve the guidelines was held in 2009².
²['Guidelines for preclinical animal research in ALS/MND: A consensus meeting. Amyotrophic Lateral Sclerosis. 2010 11: 38-45.](#)
¹['Guidelines for the preclinical in vivo evaluation of pharmacological active drugs for ALS/MND: Report on the 142nd ENMC international workshop. Amyotrophic Lateral Sclerosis 2007; 217-223](#)
- 22.5 **Reporting on work including animals**
Publication of the outcomes of work involving animals should comply with the [ARRIVE Guidelines](#) (Animal Research: Reporting of *In Vivo* Experiments) and these should also be taken into account when planning experiments, to ensure all relevant information is recorded accurately.

23 SCIENTIFIC INTEGRITY

- 23.1 In the rare event of scientific fraud occurring, the Association wishes to make it clear that it is the responsibility of the employing authority to investigate any suspected case of fraudulent activity. The Association agrees to provide funding providing the employing authority can produce evidence of a procedure for dealing with scientific fraud. If fraud should be proven the grant must be repaid in full to the Association forthwith.

24 INDEMNITY

- 24.1 The Association does not provide cover for negligent or non negligent harm for participants in Association funded studies. The host institution should ensure that local arrangements are in place should claims arise.

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APPENDIX 1: Intellectual Property rights and commercial activities.

As a charity, The MND Association is obliged to ensure that the outcomes of its funded research are applied for the public benefit. In some circumstances, this obligation may be best achieved through the protection of intellectual property resulting from the research and the facilitation of commercial exploitation of this intellectual property.

The term 'intellectual property' (IP) describes any work or invention that results from original creative thought. IP falls into different categories:

- Copyright - protects written, dramatic and artistic work, software, films, sound recordings and broadcasts
- Patents – protects technical inventions, novel products or processes
- Trademarks – distinguish the goods and services of one organisation from another
- Design rights – protects the visual appearance of products

Some of these protections need to be registered (trademarks, patents) and some do not (copyright, design rights). If the IP is not protected, another individual or organisation may copy the design or commercialise and sell the new invention without consent or payment.

Therefore, for grants where MND Association funding may lead to the generation of intellectual property, the following additional conditions shall apply:

- A1.1 The MND Association requires all grant-holding institutions to have strategies and procedures in place for the identification, protection, management and exploitation of intellectual property, including that resulting from funding by charities.
- A1.2 The institution should ensure that all persons in receipt of funding from the MND Association, or working on MND Association funded activity (including employees, students, visiting staff and sub-contractors), are employed or retained on terms that vest in the institution all intellectual property arising from funding by the MND Association.
- A1.3 The institution and the grant holders should notify the MND Association promptly in writing when IP arises from the grant. They should consult with the Association to determine the best course of action to achieve public benefit. They should take reasonable steps to ensure that such IP is protected, and not published or otherwise disclosed publicly prior to protection, whilst at the same time aiming to minimise the potential delays in publication.
- A1.4 The institution should seek the MND Association's consent before using, or authorising the use of, the intellectual property for any commercial purpose. Consent will not be unreasonably withheld, and the MND Association will only refuse an institution's request where it considers that the proposed commercial exploitation would run counter to its interests and charitable objectives.
- A1.5 As a condition of granting consent, the MND Association will require the institution or its recognised technology transfer company to negotiate appropriate revenue sharing terms, in accordance with advice from the Association of Medical Research Charities, and to adhere to a reasonable commercial strategy approved by the Association.
- A1.6 If the institution does not wish to protect, manage or exploit the IP, or fails to comply with the agreed strategy, the Association may direct the institution to take steps to protect the IP at the Association's expense or to transfer the IP to the Association.
- A1.7 If the institution wishes to use any third party (other than its recognised technology transfer company) to carry out its obligations with respect to IP, it must provide details to, and obtain prior written approval from, the Association.

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