

2021

RESEARCH GRANTS



2021 ANGIE CUNNINGHAM
PHD SCHOLARSHIP AND PROJECT
GRANT-IN-AID AWARD

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MND OVERVIEW

MND is the name given to a group of diseases in which the nerve cells (neurons) controlling the muscles that enable us to move around, speak, swallow, and breathe fail to work normally and eventually die. With no nerves to activate them, the muscles gradually weaken and waste away, and with no residual muscle strength, people with MND are left motionless, mute, and trapped within their once active bodies. In the majority, the mind and intellect are normally unaffected by MND.

The disease is also known as Amyotrophic Lateral Sclerosis (ALS), or Lou Gehrig's disease in the USA, and although patterns of weakness and rates of progression vary from patient to patient, and while some people may live a long time with MND, the average life expectancy is only 27 months from diagnosis in Australia.

MND FACTS

- The estimated lifetime risk of being diagnosed with MND varies geographically around the world, but has been reported to be between 1:350 to 1:500 in Australia and European countries, and between 1:600 to 1:1000 in the USA;
- It is estimated that there were 2094 Australians with MND in 2015, or 8.7 in 100,000 people;
- Mean survival in Australian MND patients following diagnosis is only 27 months;
- 60% of MND sufferers in Australia are male, and 40% female;
- Approximately 58% of people with MND in Australia are under the age of 65;
- The number of deaths due to MND in Australia is increasing. The latest available data from the Australian Institute of Health and Wellbeing (AIHW) shows that of the 158,493 deaths registered in Australia in 2018, 755 were MND related. MND therefore accounted for 1 in ~200 deaths in 2018.

There is currently no truly effective treatment and no known cure, so this is why we fight MND.

Sources are Deloitte Access Economics report Economic Analysis of MND in Australia and AIHW.

FightMND is a 100% not-for-profit foundation established in 2014. At FightMND, our vision is **A World Without MND** and our purpose is to champion hope and lead the fight against MND. FightMND aims to raise the profile of Motor Neurone Disease within Australia and abroad in the hopes that increased awareness may lead to not only better care for those affected by the disease, but also increased funding for vital research into finding a cure.

We are Australia's leading independent MND foundation with a strong key focus and strategy towards driving national MND clinical trials with equitable access for all MND patients throughout the country. We work closely with other national and state MND bodies, taking a lead role in the clinical trials development and provision process, doing so with a sense urgency and equality on behalf of all Australian's currently fighting this disease.

Large-scale collaborative drug development projects continue to be a primary focus of FightMND, driving exciting new research discoveries in the laboratory through phases of preclinical research, drug development and assessment necessary to advance potential therapeutics through to clinical trial.

Our **IM**proving and **AC**celerating **T**ranslation (IMPACT) research program supports novel and innovative research focused on tackling key challenges hindering the translation of promising discoveries into effective therapies, with the goal of improving the likelihood of positive MND Clinical Trial outcomes.

FightMND's primary aims are:

TO CURE

At FightMND we are passionate about funding leading research within Australia with the aim of expediting discoveries of potential treatments for MND sufferers, and ultimately to finding a cure. We do this in the hope of one day living in a world free from MND.

TO CARE

Until a "cure" is discovered and available, FightMND believes that each and every person living with MND, and their family, deserve to have the ability to continue to participate and thrive within their communities. We are passionate about providing vital equipment to MND patients in order that they may maintain independence, dignity, and an improved quality of life.

TO MAKE AWARE

FightMND will continue to push MND into the spotlight and increase the public profile of MND within the Australian and wider communities, in the hope that people, governments and pharmaceutical companies will take up the fight and join us in the quest for viable treatments, and ultimately, a cure. **It takes people.**

INTRODUCTION

FightMND Call for Proposals:

PhD Scholarship and Grant-in-Aid Awards

Applications open:	30 October 2020
Applications due:	1 February 2021, by 17:00 AEDT
Recipients notified:	March 2021

FightMND is pleased to announce a call for applications to support the training of a graduate science student in their pursuit of achieving a PhD qualification (or equivalent) while performing research directly relevant to Motor Neurone Disease (MND). FightMND call for applications for novel, innovative projects aimed at understanding the causes of sporadic MND, elucidating disease mechanisms and/or tackling one or more key issues contributing to the lack of effective treatments for sporadic MND.

Support will not normally exceed three years, and applicants must submit proposals that are focused and compatible with a 3-year timeframe. Continuation of the Award beyond the 3-year period will be subject to review, with additional funding to support a 6-month extension considered following review of submitted annual progress and financial reports over the course of the 3-year Award.

Reporting is an essential requirement of the Award (see Terms and Conditions 1.1 and 15) and should be considered when outlining your experimental and project plan.

FightMND will provide:

A total of \$100,000 AUD per annum for a 3-year Scholarship and Project Grant-in-Aid.

This funding comprises:

- A student stipend of \$30,000 per annum;
- A total budget of \$5,000 per annum for travel and conference attendance;
- \$65,000 per annum in project and laboratory expenses (Grant-in-Aid); and
- Following review and approval by FightMND, a further 6 months of funding to the value of \$50,000 is available for PhD projects extending to a 3.5-year duration.

See Terms and Conditions for further details.

ELIGIBILITY

Applications are invited from prospective supervisors of PhD students based in research institutions in Australia. The Applicant (Principal Supervisor) must have demonstrable experience of supervising PhD students.

Eligible projects for the Project Grant-in-Aid portion of this Award must fulfil the following criteria:

- Target sporadic MND;
- Within the scope of the project demonstrate a 'bench-to-bedside' potential for outcomes obtained, focused on disease control or cure;
- Be hypothesis driven with defined aims and milestones;
- Where possible demonstrate a multi-institutional collaborative approach;
- Must be conducted in an Australian research institution;
- Applicants and their institutions must commit to funding all on-costs and administrative overheads as a contribution to the project. 100% of FightMND's 'Grant-in-Aid' funding must be spent on core project costs;
- Capital equipment, depreciation, or maintenance of equipment will not be funded by FightMND;
- Any other actual or proposed sources of funding to support the project must be disclosed; and
- The project funded must be directly associated with the PhD scholarship outlined in the application and can commence as soon as it is awarded. The project must commence within 3 months of the return and receipt of a signed Award Agreement to FightMND (or the Scholarship and Grant-in-Aid shall lapse).

PERSONAL DIRECTION OF THE PROJECT

It is expected that the Applicant/Principal Supervisor will be actively engaged in directing the project and supervising the PhD Candidate.

COLLABORATORS

Where the viability of a project depends on the collaboration/involvement with an investigator or investigators not named as applicants, the exact role of the collaborator/s should be clearly stated and confirmation from each collaborator indicating their willingness to participate must be provided with the application.

ANGIE CUNNINGHAM – THE INSPIRATION

It is said that the qualities of a good PhD Student are perseverance, tenacity, courage, and the ability to communicate. The Angie Cunningham FightMND PhD Scholarship and Project Grant-in-Aid Award honours the life and qualities of a woman who was the embodiment of all of these traits and more.

Angie was a girl from Tasmania who had not only a natural ability, but an undying perseverance. She applied this to her passion – tennis. At the age of 11, she conquered the national tournament and came to the attention of sports selectors. Her tenacity saw her leave home at the age of 14 to attend the Australian Institute of Sport, and she went on to hit a peak junior doubles ranking of No. 2. Angie appeared in the Wimbledon girls' doubles final in 1991 as well as two Australian Open girls' doubles finals.

Later Angie went on to work as the Vice President of Player Relations and on-site operations at the Women's Tennis Association. Her colleagues have said that it took 3 people to replace the work that she did for years on her own.

These qualities allowed Angie to stare down the barrel of MND with steadfast courage when she was diagnosed with the devastating disease at the age of 38. A wife to Pat, and a mother of two young girls aged 6 and 3, within days of the diagnosis Angie made a firm decision to “focus on the things that I have, not what I have lost”.

Her ability to communicate and share her compassionate, loving spirit is something all her friends can attest to. She was a mentor for young tennis players, a firm support for professional tennis players and colleagues, and a true friend.

Her spoken word was full of humour and love, and it was these qualities that allowed her to navigate her journey with MND with dignity, grace and a complete appreciation for the value of life and love. She and Pat started the Laugh to Cure Campaign in 2014, before joining forces with Dr Ian Davis and Neale Daniher to form The Cure for MND Foundation and FightMND.

**Angie's legacy is that of courage,
selflessness and eternal positivity against all the odds.**

OBJECTIVES, PRIVACY AND ACKNOWLEDGEMENT

FightMND supports biomedical research in the field of Motor Neurone Disease (MND), encompassing all relevant research disciplines. The objectives of this specific FightMND PhD Scholarship and Project Grant-in-Aid Award are to:

- Support research aimed at understanding the causes of sporadic MND, elucidating disease mechanisms and facilitating the translation of therapeutic strategies from the laboratory to the clinic;
- Encourage new interest within the field of MND research from exceptional new postgraduates;
- Help develop PhD graduates who demonstrate academic leadership, independence, creativity and innovation in their work and foster a passion for future MND research;
- Honour the memory and legacy of Angie Cunningham.

FightMND only supports work carried out in bona fide research institutions.

PRIVACY, CONFLICT OF INTEREST

PRIVACY AND CONFIDENTIALITY

All information contained in applications forwarded to FightMND will be regarded as confidential. Documents containing personal information will be handled and protected in accordance with the provisions of the *Privacy and Data Protection Act 2014* (Vic). Personal information will only be disclosed with the permission of the individual to whom it relates, or where the Act allows.

Applicants consent to the information supplied as part of their application being disclosed for the purposes of the evaluation and administration of the application. Such disclosure includes but is not limited to members of the FightMND Grant Review Panel, independent reviewers/assessors, the FightMND Board and relevant employees of FightMND involved in processing and evaluating the application.

Applicants acknowledge that announcement of the Award will involve a dissemination of information to the public about the general nature of the funded Scholarship and Grant.

CONFLICT OF INTEREST

FightMND requires its reviewers and Grant Review Panel members to act in an ethical manner, declare conflicts of interest, and withdraw from considering applications where such conflict does or may exist.

ACKNOWLEDGEMENT OF SUPPORT

Successful applicants are required to acknowledge FightMND in any publications, public announcements, media, and scientific meeting presentations or discussion forums pertaining to research conducted. FightMND materials, logos and images can be supplied for this purpose, if required.

APPLICATION PROCEDURE

Applications are submitted to FightMND and are independently peer reviewed prior to consideration by FightMND's Cure Sub-Committee. The Cure Sub-Committee's funding recommendations are then considered by the Board of FightMND. Key factors in determination of awarding of this Award grant will include the:

- I. Research and supervisory track record of the Applicant (Principal Supervisor);
- II. Quality and strength of the research project/plan;
- III. Academic and track records of the PhD candidate; and
- IV. Alignment of the Project and Applicant towards the core aims and mission of FightMND.

Proposals should include the following:

- **Completed Cover Sheet** (see page 8), including:
 - Applicant and co-Applicants;
 - A 50 word lay summary of the project suitable for media release if the application is successful.
 - A 250 word lay summary of the project suitable for publication on the FightMND website and newsletter if the application is successful.
 - Provide background information necessary for readers without scientific or medical training to understand the rationale and feasibility of the proposed research project. It should also clearly describe the scientific objective the project is designed to achieve.
 - Name of the institution where the project work will be undertaken.
 - Including a letter of support from the institution confirming that appropriate infrastructure, equipment, and consumables will be available and provided for the proposed project to completion, together with support for the training and development of the PhD candidate.
- **Summary of Project** (1/2 page max.)
 - Include project Hypothesis and Aims.
- **The Project** (6 pages max.). Include:
 - Background and Supporting Data (2 pages max.);
 - Research plan (4 pages max.), including data and statistical analyses, timeline (Gantt chart), outcomes and significance;
- **References** (1 page max.).
- **Budget** (1 page max.).
 - Budget items should include:
 - Stipend for PhD candidate (max. \$30,000 p.a., no overheads or oncosts);
 - Travel for attendance at academic conferences (max. \$5,000 p.a.);
 - Direct research costs (reagents, consumables, animal costs, microscopy etc).

APPLICATION PROCEDURE

- Budget items cannot include:
 - Equipment;
 - Institution indirect or overhead costs.
- **Declaration and details of research funding from other sources (actual or proposed) that relate to the Project's hypothesis, aims and research plan**
Include:
 - Applicant, and Title of other Application;
 - Funding Source/Organisation and Application ID;
 - Role of Investigator on other Application; and
 - Total amount requested.
- **Supervisor and Institute Background (2 pages max.). Include:**
 - Career Summary;
 - Research support (last 5 years);
 - Track record of PhD supervision;
 - Statement of encouragement outlining strategy to keep the PhD candidate in the field of MND research;
 - Institute background and key research priorities.
- **A letter of support from the Administering Institution (1 page max.)**
- **Collaborators (1 page max.)**
 - Where the viability of a project depends on collaboration/involvement with investigators not named as Applicants, the exact role of the collaborator(s) should be clearly stated and confirmation from each collaborator indicating their willingness to participate must be enclosed with the full application.
- **Curriculum Vitae of PhD Candidate(2 pages max.)**
 - Prospective candidates should hold a first or upper second-class honours degree.

Attach to the application:

- Academic Transcript of the PhD candidate; and
- Two letters of reference/recommendation for the PhD candidate.

Reporting is an important requirement for the FightMND Angie Cunningham PhD Scholarship and Project Grant-in-Aid (see Award Terms and Condition 1.1 and 15). Please consider this when planning your experiments and project.

The application deadlines are described in this guideline. Minimum size font for applications is size 12 (calibri font preferred), and page margins of 1 cm. Applications are to be submitted as a single PDF document and forwarded to Dr Davor Stanic, FightMND Research Co-ordinator, at researchgrants@fightmnd.org.au before the closing date and time for applications.

COVER SHEET

2021 FightMND Angie Cunningham PhD Scholarship and Grant-in-Aid Cover Sheet

1.	Project Title (for Grant-in-Aid portion of the Award)	
2.	Title, name, qualifications and Institution of Applicant (Supervisor)	
3.	Email address of Applicant	
4.	Mobile phone no. of Applicant	
5.	Name, institution, and role of co-Applicant/s	
6.	Name of PhD candidate	
7.	Administering Organisation / Sponsoring institution administering the Award	
8.	Name of Award administrator for (6)	
9.	Contact details for (7)	
10.	Total Budget Estimates for each year	Year 1 \$ Year 2 \$ Year 3 \$ TOTAL - \$
11.	Key research area of Application	
12.	Key Words (4 minimum)	
13.	A 50 word max. lay summary of the project suitable for media release if the application is successful.	
14.	Summary/Lay description (250 words max. – use separate page if required). Describe in terms and language applicable to the general public, the overall aims and expected outcomes of this project.	

REPORTING

Funding recipients will be required to submit reports on a regular basis. The reporting schedule is outlined in the following table:

REPORT	REPORTING FREQUENCY	DUE
Progress against pre-determined milestones and/or targets*	Annually	Every 12 months from receipt of funds
Financial Reports (to be included in progress report) *	Annually	Every 12 months from the receipt of funds
Final Report	Once Only	At project completion
Ad hoc reports*	As requested by FightMND	On request with a negotiable time frame not greater than six weeks
FightMND Research Symposium Presentation (Melbourne, Vic)	Biennially	During FightMND Research Symposium

*These reports will be used to assess whether the project is proceeding satisfactorily, whether funds are being acquitted in accordance with the original application goals, and to ascertain the ongoing value of FightMND funding.

Funding may be suspended if progress is considered unsatisfactory, or if funds have not been utilised in accordance with the Angie Cunningham PhD Scholarship and Grant agreement.

TERMS & CONDITIONS

TERMS AND CONDITIONS

All communication concerning Award applications and administration should be addressed to Dr Davor Stanic, FightMND Research Co-ordinator at researchgrants@fightmnd.org.au.

1. FUNDING ARRANGEMENTS

1.1. FightMND Scholarship and Project Grant-in-Aid Awards are time limited and applicants should ensure that proper consideration is given to this in the proposal. When the project is approved in principle, the initial sum awarded by FightMND will be for the first year only. Approval of funding for subsequent years, at twelve (12) monthly intervals will be subject to the receipt, from the Applicant, of satisfactory project progress and financial reports. Members of FightMND, Cure Sub-Committee and Board will review progress reports to decide outcomes.

1.2. If the applicant under-spends in any year, FightMND 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 FightMND in advance. Requests must be made by email to Dr Davor Stanic, FightMND Research Co-ordinator, at researchgrants@fightmnd.org.au at least eight weeks prior to the original completion date.

1.3. The value of the Award is for \$100,000 per annum for a period of 3 years. The Scholarship component of the Award will cover the student stipend of \$30,000 per annum. The award will also cover research expenses directly attributable to the student's project as a Grant-in-Aid to the value of \$65,000 per annum.

1.4. FightMND will not meet indirect or overhead costs or on-costs of the Administering Institution such as: general travel, finance services, staff facilities, staff development, public relations, institutional libraries, routine secretarial work, personnel services, stationery or contributions to general departmental costs, and publication costs (except for those necessary to enable open access for publications).

1.5. Conference attendance: FightMND will allow up to \$5,000 per annum towards the cost of relevant conference attendance by the PhD candidate. This may be used during the life of the project towards the costs of registration fees and travel, but not to cover separate hotel accommodation or other subsistence costs. Invoices, receipts or other evidence of spending must be provided. The PhD candidate is encouraged to present their work, and is expected to attend and present at one relevant meeting per year.

1.6. Payment of instalments is conditional on receipt and approval of satisfactory project progress and financial reports (see Terms and Conditions 1.1 and 15.1).

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

2. EQUIPMENT

2.1. FightMND will not fund any equipment purchase as part of this Award.

TERMS & CONDITIONS

3. ETHICAL CONSIDERATIONS

3.1. It is the responsibility of the Applicant to have ethics approval for all planned research as required. This should ideally be in place at the time of applying for funding.

3.2. Ethics approvals must be received, and copies provided to FightMND upon request, prior to the Award commencing.

4. PERSONAL DIRECTION OF THE PROJECT

4.1. It is expected that the Applicant will be actively engaged in directing the project. In instances where an Applicant will have a prolonged absence from directing the project, the Applicant must advise FightMND in writing and may continue to utilise FightMND funds following approval of the nomination of another qualified investigator to oversee the direction of the project in their absence. The Applicant or an approved representative of the Administering Institution must apply to and notify the FightMND Research Co-ordinator, Dr Davor Stanic, by email to researchgrants@fightmnd.org.au with an explanation of the situation, providing details of the arrangements for conducting the research during their absence (see Terms and Conditions 11.2).

5. RECRUITMENT AND EMPLOYMENT OF STAFF

5.1. FightMND does not act as an employer and, therefore, in all cases where financial support is provided for the employment of staff, the Administering institution undertakes to issue a contract of employment in accordance with any other relevant Act relating to the conditions of employment.

5.2. FightMND will not be responsible for claims under statute or at common law, nor will they indemnify the Administering 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 Administering institution must accept full responsibility for:

6.1. The management, monitoring and control for all staff (permanent, temporary and students) employed or involved in any research funded by a FightMND Award; and

6.2. The management, monitoring and control of all research work funded as a result of a FightMND Award.

7. TERMINATION OF EMPLOYMENT

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

8. EMPLOYMENT TERM CONTRACTS

8.1. Where members of staff have been under contract to the Administering institution prior to the activation of the FightMND Award, FightMND will not reimburse costs attributed to any prior commitment. This includes any redundancy payments due for service prior to the Award period.

TERMS & CONDITIONS

8.2. The contract of employment offered must not extend beyond the termination of the Award (unless the Administering institution wishes to extend the contract at its own expense).

9. MATERNITY AND OTHER LONG-TERM LEAVE

9.1. The Administering institution will meet the cost of any long-term leave, other than holiday, and will ensure that all annual leave entitlement is taken within the Award period. Long-term leave may include maternity, paternity or long-term sick leave.

9.2. Maternity or paternity leave is the responsibility of the Administering institution employing staff undertaking a FightMND project. Leave will be provided according to the Administering Institution's local terms and conditions of employment. The costs of such leave are the responsibility of the Administering institution and are not provided for by FightMND.

9.3. If a FightMND-funded employee is due to take any planned long-term leave, the Award holder should inform FightMND of the dates in advance. This will enable discussion to decide whether the Award should be suspended for the period of absence until full-time employment can be resumed (see Terms and Conditions 4 and 11.2). If unplanned long-term leave occurs, the Award holder or an authorised representative of the Administering Institution should contact FightMND as soon as possible to discuss the situation with the Research Co-ordinator.

10. ACTIVATION OF AWARD

10.1. The Award is activated on receipt of a signed Grant Agreement and receipt of the first invoice. If, for any reason, the start date of the project is delayed after the Grant Agreement has been returned, FightMND must be informed at once, a *Grant Agreement Amendment Application* completed, and a new start date agreed (see Terms and Conditions 11.2). If necessary, a revised Grant Agreement will need to be completed and returned.

10.2. If the project does not start within three (3) months of the original agreed start date stated in the Award Agreement, FightMND may withdraw the Award offer. The Applicant will have to reapply for funding in a future round, in competition with other applicants at the time.

10.3. Ethical Approval: FightMND 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 Applicant to have ethical approval for the proposed research 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 of the approved budget to another, as detailed in the Grant Agreement, requires written permission from FightMND.

11.2. Applicants will be required to complete a *Grant Agreement Amendment Application* 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, and submitted for approval to the FightMND Research Co-ordinator, Dr Davor Stanic, by email at researchgrants@fightmnd.org.au. FightMND must be kept informed at all times of any change to the original Award and the Grant Agreement.

TERMS & CONDITIONS

11.3. Any request for major changes in the terms of the Award, e.g. for additional staff or budget items, must be made in the form of a new and separate grant application, which will be considered in competition with all other new applications.

12. CHANGES TO CONDITIONS OF THE AWARD

12.1. FightMND reserves the right to change the Terms and Conditions of the Angie Cunningham PhD Scholarship and Grant-in-Aid Award at any time. If this occurs during the lifetime of this Award, the revised Terms and Conditions may be applied in place of those issued at the commencement of the original Award.

12.2. Successful Applicants will be given at least 8 weeks' notice of any change to conditions of the Award.

13. EARLY TERMINATION OF AN AWARD

13.1. FightMND reserves the right to terminate an Award 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 three months of the agreed start date;
- The work is diverging markedly from the original approved project. The Applicant/Supervisor must inform FightMND immediately when they are aware of a change of direction (see Terms and Conditions 11.2). There may, however, be circumstances in which the change is acceptable on scientific grounds;
- Failure to submit adequate progress reports, or serious and unresolvable problems identified by a site visit; and
- Work has stopped on the Award, or the Applicant/Supervisor has ceased to be actively involved in the Project/Award. FightMND must be informed immediately if the situation arises (see Terms and Conditions 11.2).

FightMND will endeavour to give 60 days' prior notice before termination of an Award.

13.2. If an Award is terminated, FightMND will meet costs properly and necessarily incurred under the Award's Grant Agreement up to the termination date. However, payments will not, in aggregate, exceed the amount of the Award remaining to be paid at the time of its termination.

13.3. In the event of work being discontinued by the Administering institution, written notification must be sent to FightMND, together with a report on the work carried out to date, setting out reasons for the termination.

14. EXTENSION TO AWARDS

14.1. It is the responsibility of the Applicant/Supervisor 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 Terms and Conditions 11.2).

14.2. Adequate time (at least eight weeks), should be allowed for an application to be processed and FightMND accepts no responsibility for any costs incurred due to the failure of an Applicant/Supervisor to make such an application in good time.

TERMS & CONDITIONS

15. REPORTS

15.1. The Applicant/Supervisor in consultation with the PhD Candidate is required to submit the following reports:

- **Annual progress reports:** due every 12 months after the Award's start date, as stated on the Award Grant Agreement (see Terms and Conditions 1.1). A short summary in language intelligible to the lay reader should also be submitted for possible use in FightMND publications and on our website;
- **Final report:** required within six weeks after Award completion. A detailed final report covering the whole project will be substituted for the annual report. In addition, a summary should also be provided in language intelligible to the lay reader. Applicants/Supervisors and the PhD Candidate must avoid the use of jargon and technical language and should pitch the summary at the level of a science feature in a broadsheet newspaper. The summary may be used in FightMND publications; and
- **FightMND Research Symposium:** the PhD candidate is required to present progress of the Award project annually, and at the FightMND Research Symposium.

15.2. The final instalment of the Award will be paid only after receipt of the final report and its approval by FightMND. Payment may be delayed further if reports are not submitted on time and/or if clarification is required.

15.3. Thesis: in addition to the final report, FightMND must receive an electronic copy of the submitted and final versions of the PhD Thesis, when available.

15.4. Feedback to people living with MND and/or Carers. All Applicants/Supervisors and PhD candidates are encouraged to provide regular information on their research to be circulated by FightMND for patients and carers. Where volunteers are involved in research, Awardees are required to provide regular feedback to the participants and FightMND, in addition to annual reports and publications.

16. SITE VISITS AND PROGRESS MEETINGS

16.1. FightMND reserves the right to visit the Applicant's laboratory during the period of the Award to discuss progress, and welcomes invitations to do so.

16.2. The Applicant may be asked to attend six-monthly progress meetings to discuss progress with FightMND representatives and donors. These may be arranged in conjunction with site visits.

16.3. The Applicant and PhD candidate may be asked to take part in FightMND communication projects such as video content to help facilitate feedback to FightMND's donors on outcomes related to the Award.

17. PUBLICATIONS, PRESENTATIONS, ACKNOWLEDGMENTS AND PUBLICITY

17.1. Applicants are expected to seek publication of findings in refereed journals during and as soon as possible during and after conclusion of the Award (subject to Term and Condition 18). FightMND and the Applicant jointly undertake to notify each other before published reference is made to the findings of the project, and to discuss the form of publication wherever possible.

TERMS & CONDITIONS

17.2. Applicants must inform FightMND immediately when results from FightMND-funded research are accepted for publication or presentation. The Applicant must provide FightMND with reprints, photocopies or electronic copies of the final version of any such publications.

17.3. **Open Access Policy:** Applicants of Awards from FightMND are mandated to make their peer-reviewed papers, directly arising from the Award, available through open access. These research papers should be available within the PubMed Central repository as soon as possible, but definitely within six months of publication. Costs to enable open access for publications can be included in the project budget.

17.4. **Posters – costs and accessibility:** If FightMND-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 \$250 per Award). The poster must acknowledge FightMND as a source of funding and should include FightMND's logo. FightMND should be provided with an electronic copy of the poster for use on our website and social media.

17.5. To ensure the long-term sustainability of income for research and to reflect and maintain our reputation for funding research of the highest scientific excellence and of greatest relevance to MND, all opportunities to promote FightMND must be pursued. The Applicant and the Administering institution are obliged to co-operate with FightMND over any publicity or fundraising activity arising from research funded by FightMND. Where it is the main funder of the research, FightMND reserves the right to lead on publicity.

17.6. Applicants and the Administering institution must notify FightMND's Research Co-ordinator Dr Davor Stanic by email to researchgrants@fightmnd.org.au, Research Director Dr Bec Sheean at research@fightmnd.org.au and Communications Manager Andrew Holmes at andrew@fightmnd.org.au at least five working days in advance of any publicity arising from research wholly or co-funded by a FightMND Award or Grant. FightMND must be given at least 24 hours' notice of any media release in connection with the funded project. Any press release or other material including reference to FightMND-funded research must be approved by our team before it is released to the media.

17.7. In any oral or written report or poster presentation relating to FightMND-funded research, the awardee and/or author must acknowledge our support and display the FightMND logo where practical. All references to FightMND-funded work placed on websites, electronic bulletin boards and similar platforms must state clearly that the work is funded by "FightMND" and ideally a link should be included to FightMND's website: www.fightmnd.org.au.

17.8. The Applicant and the PhD candidate must ensure that FightMND's support is acknowledged in all publications, presentations and similar communications. It is essential for Applicants and the PhD Candidate to acknowledge that their research has been supported wholly or in part by FightMND, either in the text or in a footnote. The Award reference/ID must also be provided.

TERMS & CONDITIONS

17.9. When speaking publicly and to representatives of the media about FightMND-funded research, Applicants and the PhD candidate should ensure they make it clear to the media and others that they should be presented as a “FightMND-funded scientist”. Applicants and the PhD candidate should consult with FightMND’s Research Director Dr Bec Sheean at research@fightmnd.org.au and Communications Manager Andrew Holmes at andrew@fightmnd.org.au, before speaking to the media.

17.10. There is a subtle but important difference between speaking as a “FightMND-funded scientist” and acting as a spokesperson for FightMND. Representatives of the media may not always be aware of this difference. Awardees and Researchers who speak to the media must ensure that their personal views are not misrepresented as being attributable to FightMND.

18. PATENTS, COPYRIGHT AND OTHER INTELLECTUAL PROPERTY

18.1. If ideas, processes or products of potential commercial value are generated as a result of the project, the Applicant and/or Administering Institution must obtain the written consent of FightMND before taking any steps to exploit the results commercially. The Applicant and Administering Institution accepts that FightMND 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 Award. For further detail, please see Appendix 1 – Intellectual property rights and commercial activities.

19. FIGHTMND MEETINGS AND EVENTS

19.1. Applicants and the PhD Candidate are asked to make themselves or other appropriate research team members available to report on the Project and Award at FightMND meetings, fundraising events and occasionally at other times by invitation.

19.2. There may be occasions where the Applicant and/or PhD candidate will be asked to present their work relating to the Award at scientific and or health care professionals’ meetings.

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

20. FIGHTMND CASE STUDIES

20.1. Applicants and the PhD candidate are asked to make themselves available as case studies reflecting the work of FightMND for its wide-ranging communications and fundraising activities.

21. SCIENTIFIC INTEGRITY

21.1. In the rare event of scientific fraud occurring, FightMND wishes to make it clear that it is the responsibility of the employing authority to investigate any suspected case of fraudulent activity. FightMND 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 Award (i.e. Scholarship and Grant-in-Aid) must be repaid in full to FightMND forthwith.

TERMS & CONDITIONS

22. INDEMNITY

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

APPENDIX 1

INTELLECTUAL PROPERTY RIGHTS AND COMMERCIAL ACTIVITIES

As a charity, FightMND 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 FightMND funding may lead to the generation of intellectual property, the following additional conditions shall apply:

1.1. Any intellectual property developed during the course of conducting research supported by FightMND Awards under this agreement (Project IP) shall be owned by the Administering Institution.

1.2. The Administering Institution must comply with the National Principles of Intellectual Property Management for Publicly Funded Research by having in place strategies, policies, and procedures for the identification, protection, management, and exploitation of intellectual property, including that resulting from funding by charities such as FightMND.

<http://www.arc.gov.au/national-principles-intellectual-property-management-publicly-funded-research>

1.3. The Administering Institution should ensure that all persons in receipt of funding from FightMND, or working on 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 FightMND.

1.4. The Administering Institution, Applicant, co-Applicants and PhD candidate should inform FightMND of any pre-existing arrangements of which they are aware and which could lead to a breach of FightMND-funded standard conditions. The institution should take reasonable endeavours to ensure that no consultancies, third party restrictions or arrangements which might impact on a FightMND-funded grant are entered into in relation to any FightMND-funded person or activity without prior agreement of FightMND. FightMND-funded investigators or individuals involved in a FightMND-funded project should not use materials or compounds (other than those obtained commercially), on terms which would place restrictions on the publication of the results. Institutions should take reasonable endeavours to ensure that “reach-through claims” have not been

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granted on any FightMND-funded IP in favour of commercial organisations providing materials or compounds to FightMND-funded individuals for research purposes. However, FightMND recognises that companies providing materials may often require exclusive rights to any intellectual property arising from use of that material, and that this requirement is often non-negotiable. Where intellectual property arises from research linked indirectly to the use of material provided under such agreement, the provider should be offered a time-limited opportunity to take out a revenue generating licence.

1.5. The Administering Institution, Applicants, co-Applicants and the PhD candidate are bound to notify FightMND promptly in writing when new Project IP arises from the Award and 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 ensuring that potential delays in publication are minimised).

1.6. The Administering Institution should seek FightMND's consent to commercially exploit the results of any research it has funded. Consent will not be unreasonably withheld, and FightMND will only refuse an Administering Institution's request where it considers that the proposed commercial exploitation would run counter to its interests and charitable objectives. In the event that FightMND does not provide a response to the Administering Institution's request within thirty days, the institution or its technology transfer subsidiary will automatically have the right to proceed with such commercial exploitation. The Administering Institution is not required to seek FightMND's consent in assigning intellectual property to its technology transfer company.

1.7. Within 30 days of receiving the notification from the Administering Institution, and prior to the Administering Institution applying for registration of any Commercial IP, FightMND will advise the Administering Institution in writing which one of the following financial arrangements will apply in relation to commercialisation of the Commercial IP:

- I. All of the costs associated with commercialising of the Commercial IP (including patent and legal costs) will be paid by the Administering Institution. Out of any net proceeds received by the Administering Institution from commercialising the Commercial IP (after all of the Administering Institution's costs associated with commercialising the Commercial IP have first been deducted), the Administering Institution will pay 10% of all net commercialisation proceeds to FightMND until such time as FightMND has received an amount equal to the amount of the Award funding provided under this agreement multiplied by five (5).
- II. Ten per cent (10%) of the costs associated with commercialising the Commercial IP (including patent and legal costs) will be paid by FightMND as and when the costs fall due, and the remaining 90% of the commercialisation costs will be paid by the Administering Institution. Out of any net proceeds received by the Administering Institution from commercialising the Commercial IP (after all the Administering Institution's costs associated with commercialising the Commercial IP have first been deducted and FightMND's costs have been reimbursed), the Administering Institution will pay 10% of all net commercialisation proceeds to FightMND in perpetuity.

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III. FightMND will not seek any payment from the net commercialisation proceeds arising from commercialisation of the Commercial IP.

1.8. If the Administering Institution does not wish to protect, manage or exploit the IP, or fails to comply with the agreed strategy, FightMND may direct the Administering Institution to take steps to protect the IP at the Administering Institution's expense or to transfer the IP to FightMND.

1.9. If the Administering 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, FightMND.