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CLINICAL RESEARCH TRAINING GRANTS POLICY

Clinical Research Training Grants (CRTGs) awarded by the Muscular Dystrophy Association ("MDA") are governed by the policy set forth herein.

MDA supports research aimed at developing treatments for the muscular dystrophies and related diseases of the neuromuscular system. These are the muscular dystrophies (among which are Duchenne and Becker); motor neuron diseases (including ALS and SMA); the peripheral nerve disorders (CMT and Friedreich's ataxia); inflammatory myopathies; disorders of the neuromuscular junction; metabolic diseases of muscle as well as other myopathies.

The CRTG is part of the Translational Research Program, which has the mission of identifying and overcoming the inherent regulatory, cultural, financial and logistical barriers to bringing to market new therapeutic drugs or biologics for neuromuscular disease.

[Terms of this policy are subject to revision or alteration at any time.](#)

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SECTION A

PROGRAMS AND APPLICATIONS

I. TYPE AND PURPOSE OF CRTGs

The CRTG is designed to provide promising young clinicians the research training opportunities needed to become productive clinical investigators in neuromuscular disease research. This training opportunity is intended to be compatible with the requirements of a traditional clinical fellowship in neuromuscular disease and any forthcoming requirements for certification in neuromuscular disease. Trainees will be expected to design their own educational plans and to participate, under the supervision of a mentor, in the development and/or coordination of a clinical research project. At minimum, trainees should gain experience in the basic epidemiological methods of clinical research, ethical and legal issues, and the principles involved in monitoring patient-oriented research, including regulatory requirements and quality assurance. Recipients are also encouraged to acquire knowledge of and exposure to research technologies, large dataset management, bioinformatics and other research tools, as well as to develop the communication and collaboration skills necessary for successful investigator development. Clinical Research Training Grants will be awarded annually to no more than two qualified Recipients for the amount of \$90,000 per year for two years.

II. AWARD REQUIREMENTS

Applicants must:

1. Complete a core selection of coursework on clinical research in the first year of the grant. Coursework should include, but does not have to be limited to:
 - biostatistics
 - epidemiology
 - ethics/responsible conduct of research
 - study design/clinical trials design
 - use of human subjects
 - scientific writing/grantsmanship, and
 - good clinical practice
2. Participate in the design and conduct of a mentored clinical research project on human neuromuscular disease in year two;
3. Over the course of the two-year fellowship, participate in the equivalent of at least 6 months full-time patient care (including inpatient and outpatient care);
4. Dedicate 100% of full-time professional effort (the applicant's department chair or program director must provide a letter of support confirming protected time);
5. Produce a detailed progress report within 6 months from the start date of the grant, at the end of year one, and 18 months to include proof of successful completion of coursework, a detailed clinical research project plan, mentor letter, and report of expenditures. The trainee and mentor should each include information about the trainee's future plans, particularly relating to his or her transition to an independent clinical researcher;
6. Produce a final report, due at the end of year two, which includes a project update, a mentor letter/review, and report of expenditures
7. Agree to tracking of his or her career development for at least five (5) years beyond completion of the clinical research training grant.

III. APPLICATION PROCEDURE

Grant applications are made available to qualified applicants only. An application may be submitted and accepted at MDA's sole discretion and is based on the nature of the program proposed and the qualifications of the applicant. In order to receive an application, a Letter of Intent must be completed and submitted through MDA's online grants management system, proposalCENTRAL, for review.

IV. DEADLINE DATES

1. The Letter of Intent (LOI) is due December 15 for a grant to begin the following July 1,
2. The completed application must be submitted through proposalCENTRAL by January 15 for a grant to begin the following July 1.

Should a deadline fall on a weekend or US holiday, it will be extended to the next business day.

V. APPLICATION REVIEW

Quality of Applicant: Applicant should demonstrate a commitment to clinical research in neuromuscular disease and a track record of general excellence. The applicant will be asked to provide a statement outlining, briefly, the proposed curriculum and research project, his or her future career plans related to clinical research in neuromuscular disease, and how the training grant experience will help to facilitate the achievement of these career goals. The mentor must submit a statement of support addressing the applicant's qualifications and ability to complete the grant requirements. A co-mentor, if any, will also be asked to provide a letter of support. Two additional letters of support, from persons familiar with the applicant's training and qualifications, are also required.

Quality of Mentor and Environment: Reviewers should consider the adequacy and nature of the research conducted by the mentor, the mentor's ability to expose the recipient to clinical research principles as described in the purpose of this award, and the ability of the mentor's institution to provide resources and support necessary for completion of the grant requirements. The mentor will be asked to provide a statement describing how he/she will participate in the training of the applicant.

Educational Training Plan: The plan must be developed by the applicant and should list specific educational goals consistent with the purpose of the grant and explain how the goals will be achieved. The plan should also contain a detailed section describing how requirements for core coursework will be met in the first year of the award. The plan should also briefly outline a clinical research project to be conducted in year two, describing the rationale for the project and the resources available to support it (note: applicants are not expected to have detailed project plans at the time of application for this grant). Recipients who indicate that, simultaneously, they will be seeking certification in neuromuscular disease should include the elements required for certification in the educational plan.

VI. PATENT AND LICENSING POLICY INFORMATION

Grants are subject to the Association's Patent Policy. By accepting a grant offered through MDA's Research Program, the Principal Investigator, all personnel contributing to and working on the respective project, as well as the institution with which they are affiliated, agree to be bound by the terms and conditions of MDA's most recent policy on patents and licensing as described in Exhibit 1.

SECTION B **CRTG PROGRAM**

I. ELIGIBILITY FOR CRTGs

Those eligible to apply for an MDA Clinical Research Training Grant must:

1. Hold a Doctor of Medicine or Doctor of Osteopathy degree and be licensed to practice medicine in the state in which the grant will be given;
2. Be board eligible or board certified in neurology, child neurology or physical medicine and rehabilitation at the time of the award. Clinicians who have been in a practice focused on neuromuscular diseases for not more than 5 years are also eligible to submit an application;
3. Be a professional member at an appropriate educational, medical or research institution within the United States;
4. Be a U.S. or Canadian citizen, resident alien, or nonresident alien with a valid employment authorization;
5. Have an identified mentor with adequate resources to facilitate completion of the training grant; mentor must hold doctorate of Medicine or Osteopathy and should have appropriate experience in clinical or translational research in the area of neuromuscular disease.

II. DURATION OF GRANTS

Clinical Research Training Grant awards are for two years. Payment for year two is contingent upon satisfactory completion of required coursework, approval of the planned clinical research project, availability of research funds, submission of applicable institutional requirements for human subject protection and animal care, and the receipt of a satisfactory mentor letter.

III. DELAY IN ACTIVATION

The activation of a CRTG by the Principal Investigator may not be delayed. A Principal Investigator who is unable to begin his or her grant on its designated start date must relinquish the award and reapply. All Institutional and Regulatory approvals must be submitted, approved and distributed to appropriate offices, including MDA prior to the release of funds.

IV. GRANT PAYMENT

Checks are made payable to the Recipient's institution and are issued quarterly, based on completion of required activities. The institution's financial officer should establish an account from which expenses may be paid under the terms of the approved award.

All coursework must be approved in advance of enrollment. Reports of expenditures will be required at the end of year one before funding is released for year two.

V. AUTHORIZED EXPENSES

The maximum award amount is \$90,000 per year. When MDA deems them justified, the expenses identified below are permitted under the MDA CR-TG program:

1. Recipient's salary is permitted up to a *maximum* of 100% but not to exceed a total of \$85,000, inclusive of fringe benefits. A 100% effort is required.
2. Of the funds remaining after salary and fringe benefits are subtracted, up to \$10,000 can be used to pay for the following expenses:
 - a. Fees for tuition, registration or other expenses relating to coursework needed to fulfill the requirements of the grant (not limited).
 - b. Purchase of computer hardware (i.e., laptop) and/or software, limited to a total maximum of \$1,500.
 - c. Travel expenses:
 1. Travel and accommodations directly related to course completion (not limited).
 2. Travel and accommodations directly related to clinical research project (not limited).
 3. Travel and accommodations for the purpose of reporting the results of MDA-supported research at suitable scientific or medical meetings (limited to an annual maximum of \$1000).

Note: All unexpended funds must be returned to MDA upon completion of the grant.

VI. UNAUTHORIZED EXPENSES

The following expenses are not permitted under the MDA research grants program:

1. Salary or fringe benefits for mentor;
2. Salaries, travel and/or housing related to sabbatical leaves;
3. Salaries for secretarial and/or clerical staff;
4. Purchase or rental of office equipment; (i.e., typewriters, word processors, furniture, filing cabinets, and copy machines) except for laptop computer as noted above;
5. Expenses normally covered by the indirect cost of the Trainee's institution;
6. Membership dues, subscriptions, books or journals;
7. Expenses for or related to moving from one institution to another.

VII. SUPPORT FROM OTHER SOURCES

An applicant may not apply for, use or accept MDA funds for a Clinical Research Training Grant already supported for the SAME PURPOSE by funds from another public or private source.

VIII. UNEXPENDED FUNDS

If funds are not completely expended at the end of a support year, they must be returned to the Association within twelve (12) weeks of the support period. Under exceptional circumstances, a carry forward of funds may be requested. Carry over of unexpended funds is limited to a maximum of ten (10) percent of the award for that budget year. Such a request must be submitted in writing no later than four (4) weeks after the termination date of that year of support. The request must state the amount that remains unexpended and how those funds will be used in the following year. All category maximums remain in effect.

IX. EXPENDITURES BEYOND GRANT EXPIRATION DATE

Expenditures may not be committed against a grant after its expiration date except when authorized in writing by MDA's Research Department. As well, a deficit balance at the end of a support year may NOT be carried forward into a new funding year. The originally approved budget remains in effect throughout the extension period including all category maximums.

X. NO COST EXTENSION

Under exceptional circumstances, a project may be extended for a period of either three (3) or six (6) months beyond the grant's original expiration date. The Principal investigator must request such an extension in writing stating the funds remaining and a detailed justification for the extension satisfactory to MDA. The request must be made no later than four (4) weeks BEFORE the termination date of the award. The originally approved budget remains in effect throughout the extension period, inclusive of all category maximums.

XI. CHANGE IN STATUS

The continued use of grant funds following any major change in status of the Recipient requires prior written authorization from MDA. As described below, such changes include but are not limited to prolonged absence, change in institution, or withdrawal from the project.

1. PROLONGED ABSENCE

The Recipient must notify MDA of unexpected absences as soon as possible. For planned absence, the recipient must write to the MDA Research Department requesting such authorization at least six (6) weeks before the starting date of the period of absence. The request must contain an explanation of the reasons for the absence and details about the arrangements made for continuing the research training. The letter must include the following:

- a. Inclusive dates of absence;
- b. Reason(s) for absence;
- c. Letter from mentor and chairman/dean stating that the Recipient can continue training upon his/her return.

When a request for continued use of grant funds during a prolonged absence is not authorized, the grant is terminated and all unexpended funds plus unexpended accrued interest, if any, must be returned to MDA accompanied by a Report of Expenditures within eight (8) weeks of the date of termination.

2. RELOCATION OR CHANGE OF MENTOR

In the event that the Recipient's mentor relocates to a new institution during the term of the award, a letter must be sent to the MDA Research Department requesting authorization at least eight (8) weeks before the effective date of change in institution. The letter must include:

- a. Effective date - month/day/year - of change in institution;
- b. Complete address of the new institution. The new mailing address of the Recipient and mentor should also be included if it differs from that of the new institution;
- c. Revised educational plan for fulfilling the aims of the CR-TG.

If the mentor relocates, the Recipient may transfer to the new institution, structure a plan of remote communication and support, identify a new mentor subject to approval by MDA (see below), or return any unexpended funds and terminate the grant.

In order for a new mentor to be authorized, the new mentor must submit the same letters and statements required of the original mentor during the application process: a letter supporting the qualifications of the Recipient, and a statement describing how the mentor will participate in the training process of the Recipient. The candidate must submit a revised application cover sheet and a revised educational plan. All such submissions are subject to approval by MDA.

When continuation of the training grant and/or a transfer of funds to a new institution are authorized, a new application cover sheet signed by the Recipient's new institution is required. MDA's Research Department will provide instructions for transfer of funds between institutions.

When a transfer of institution or mentor is not authorized, the grant is terminated and all unexpended funds plus unexpended accrued interest, if any, must be returned to MDA accompanied by a Report of Expenditures within eight (8) weeks of the termination of that award.

3. WITHDRAWAL FROM GRANT

When a Recipient withdraws from the Clinical Research Training Grant, his/her grant terminates and all unexpended funds plus unexpended accrued interest, if any, must be returned to MDA accompanied by a Report of Expenditures within eight (8) weeks of the withdrawal.

4. CANCELLATION OF GRANT

If, for any reason, the Recipient of the Clinical Research Training Grant must relinquish the award, the Recipient should promptly notify MDA's Research Department in writing. The notification should state the effective date of cancellation of the grant. Unexpended grant funds plus unexpended accrued interest, if any, must be returned to MDA accompanied by a Report of Expenditures within eight (8) weeks of the cancellation date.

MDA reserves the right to cancel a grant if circumstances render the individual on whose behalf the award was made unfit, unqualified and/or unable to accomplish the aims of the grant. Such circumstances include, but are not limited to, abandonment of the project, loss of license, conviction of a crime, or withdrawal of insurance or other material institutional protections.

MDA also has the option of canceling an award at anytime with notice for any of the following reasons:

1. If within ninety (90) days from the scheduled funding start date MDA does not receive proof of applicable institutional Human Subject Protection or Animal Care Policies or if within one year of the scheduled funding start date MDA does not receive proof of required coursework completion;
2. Availability of Association resources are limited to the extent that continuation of funding of research grants must necessarily be placed on temporary or indefinite hold;
3. For any violation of the guidelines discussed above.

XII. CURRICULUM VITAE/BIOSKETCH

Curriculum vitae from the applicant and mentor of the Clinical Research Training Grant must be provided to MDA with the grant application.

SECTION C RESEARCH REPORTS AND PUBLICATIONS

I. REPORT OF EXPENDITURES

A Report of Expenditures form is available for upload, through proposalCENTRAL, to the financial officer of the Principal Investigator's institution. The financial officer of the institution must, within twelve weeks of the conclusion of the grant, upload the completed form to MDA and mail a check in the amount of all uncommitted and unexpended funds plus any unexpended accrued interest. When unexpended funds are not returned within sixty days of the receipt of the Report of Expenditures, the Report of Expenditures will be considered unacceptable and will be returned to the financial officer of the awarded institution. In such cases, MDA will expect the financial officer to remit payment in full within four (4) weeks. In certain circumstances, MDA may withhold the unexpended funds balance from a new grant to the PI if necessary.

Upon a cancellation or transfer of a grant, unexpended grant funds plus unexpended accrued interest, if any, must be returned to MDA and a Report of Expenditures must be submitted within eight (8) weeks of the cancellation/transfer date.

II. REPORT OF PROGRESS

Progress reports must be submitted at least eight (8) weeks prior to the 6, 12 month and 18 month points of the grant. A final report must be submitted no later than four (4) weeks following the grant termination date. MDA may require additional progress reports at any time during an award period as a condition of continuing the award.

III. PUBLICATIONS, SCIENTIFIC PRESENTATIONS AND NEWS RELEASES:

MDA's Research Department expects timely publication of the results of all research projects it supports in academia and requires that every such publication or presentation - whether in peer-reviewed journals, meeting abstract formats, platforms, and poster presentations or in review articles or similar publications - contain the following statement or its equivalent: "Supported by MDA."

Funds to support MDA's research program come primarily from donations from private citizens. It is essential to the growth and maintenance of MDA and its research program that these donors as well as individuals and families affected by the neuromuscular diseases covered under its programs are kept fully informed of research progress. For these purposes MDA often issues press releases on newsworthy research developments and produces various publications for the public that report research activities. Such a press release or report may be issued on the occasion of the publication of an article in a professional journal or a presentation at a scientific or medical meeting.

To avoid misinterpretation of research results or the raising of false hopes about a possible treatment or cure for diseases covered under MDA programs, the Association requires the cooperation of the Principal Investigator in providing MDA's Research Department with advance prepublication copies of all articles and abstracts reporting the results of MDA-supported research which MDA shall keep confidential. MDA also requires the cooperation of its Principal Investigators in participating in interviews as MDA may deem necessary. This cooperation will enable MDA to prepare press releases or other reports MDA issues on the research it supports.

All MDA Translational Research Grants are subject at minimum to the terms of MDA's Translational Research Grants Communications and Confidentiality Policy (Exhibit 2)

SECTION D **HUMAN AND ANIMAL SUBJECTS/TISSUES**

I. RESEARCH PROTOCOL

When human subjects, tissues and/or materials are to be used in a research project, it is the responsibility of the Principal Investigator and the institution to ensure that the institution has the following on file:

1. A complete copy of the research protocol approved by the Institution's Human Subjects Review Board and a copy of that Board's current approval notice;
2. A copy of the patient informed consent form(s) to be used.

A copy of the Board's current approval notice and a copy of the patient informed consent form must be submitted with the application and upon renewal.

Projects must be in compliance with all policies, rules and regulations governing clinical trials including those of the federal regulatory agencies, the respective university and institution and MDA. MDA must be advised about any amendments to the original research protocol (including the participant consent form) occurring prior to the commencement of or during the course of the research project.

II. FOOD AND DRUG ADMINISTRATION

When experimental drugs and/or experimental medical devices are to be administered to patients, the materials required in the "Research Protocol" section "D" of this document are necessary. In addition, it is the responsibility of the Principal Investigator and the institution to ensure that the institution has the following on file:

1. A complete copy of the Investigational New Drug (IND) and/or Investigational Device Exemption (IDE) application approved by the Federal Food and Drug Administration (FDA) and a copy of the FDA's approval notice; and
2. Copies of all correspondence during the application and award periods between the FDA and the MDA Principal Investigator pertaining to the experimental drug(s) and/or device study.

III. PATIENT CHARGES

MDA requires that patients participating in experimental drug and/or device studies not be charged directly for any research procedures included under the project's approved protocol. Patients must be fully advised about their responsibility for ancillary costs relating to participation in a research project -- travel, lodging, food, etc.

IV. ANIMAL RESEARCH

MDA investigators should use animals and animal tissues for research purposes only when reasonable and practical alternatives do not exist. When attainment of the specific aims of a project require the use of animals and/or animal tissues, a detailed justification must be included in the research grant application submitted to MDA. The justification shall include statements confirming that institutional guidelines:

1. Are at least as protective as those of the National Institutes of Health;
2. Conform to all applicable laws and regulations;
3. Meet prevailing community standards for responsible scientific research;
4. Apply throughout the project to ensure the humane treatment of any animals involved in the project.

It is the responsibility of the institution to ensure that no MDA funds will be released for research involving humans and/or animals until the required documentation described above is on file with the appropriate official at the institution as well as MDA.

V. CONFLICT OF INTEREST

Any potential conflict of interest the Recipient or the Recipient's Mentor may have relating to the project must be revealed. Such conflict would include (but may not be limited to) having a proprietary interest that may be affected by the outcome of a research project. It is expected that MDA grantees will observe the highest ethical standards in the conduct of research.

Exhibit 1:

PATENTS AND LICENSING POLICY OF MUSCULAR DYSTROPHY ASSOCIATION, INC.

All grants by the MUSCULAR DYSTROPHY ASSOCIATION, INC. ("MDA") are subject to MDA's Policy on Patents and Licensing. By accepting an MDA award for a research project, the Principal Investigator or other personnel contributing to and working on the Project, as well as the Institution(s) with which they are affiliated, agree to be bound by the terms and conditions of MDA's Patents and Licensing Policy. MDA understands that patents and licensing agreements may be sought on inventions resulting from research by the grant recipient supported in whole or in part by funds furnished by MDA; that such inventions should be administered so that they are introduced into public use as soon as practicable; and that such result will be achieved through granting permission to patent and license such inventions. Accordingly, it adopts the following policy:

1. An invention (hereinafter "MDA invention") resulting from the support in whole or in part to the grant recipient of funds awarded by MDA shall be reported to MDA promptly in writing. The inventions hereinafter contemplated shall include those made by employees or agents of the Institution or Investigator and third parties under the control of Institution or Investigator.
2. If the university or other research institution or an individual investigator(s) associated therewith ("Institution" or "Investigator") which is the recipient of financial support for the work leading to the MDA invention, has an established patent and licensing policy and procedure for procuring and administering inventions which are known to and accepted by MDA, or has an agreement with another organization, including agencies or departments of the U.S. Government relating to the MDA invention due to joint support, MDA will defer to that policy or agreement on the following terms:
 - a. With respect to any MDA invention, the Institution or Investigator shall have the right to file a patent application thereon, and if it wishes to do so, shall file such a patent application within a reasonable time and notify MDA thereof in writing. If MDA has not received such notification and believes that a patent filing is necessary in order to protect valuable rights in the MDA invention, it may notify the Institution or Investigator in writing of its intent to file a patent application, and if the Institution or Investigator does not thereafter, within such reasonable time as may be necessary to avoid loss of rights, file a patent application and notify MDA in writing thereof, or notifies MDA in writing that it has decided not to file a patent application, MDA, to the extent legally permissible, shall have the right to file a patent application thereon, and Institution or Investigator shall reasonably cooperate, at MDA's expense, in making such filing, and in conveying title thereto (and of all corresponding foreign and international patent rights and priorities) to MDA.
 - b. The Institution or Investigator will notify MDA in writing of any decision not to continue the prosecution of a patent application, pay maintenance fees, or defend a reexamination or opposition proceeding on a patent, in any country, not less than thirty days before the expiration of response period required by the relevant patent office. The Institution or Investigator will convey to MDA, upon written request, title to any such patent application or patent.
 - c. The Institution or Investigator will make the invention available for commercial licensing upon reasonable terms and conditions.
 - d. From the monies, if any, received from licensing the invention, MDA and the Institution or Investigator and all other parties shall share on terms mutually agreed upon by the Institution or Investigator and MDA, such terms to be determined prior to any licensing or commercial exploitation of the invention, on terms that reasonably reflect the proportion of funding that MDA has provided for the specific research project through grants and awards.
 - e. In the event that it obtains a patent, license arrangement or other commercial exploitation of an MDA invention, the Institution or Investigator shall promptly notify MDA in writing thereof, and, no less frequently than annually, make periodic reports to MDA with respect to the utilization of the invention and account for any income received by it by reason of exploitation of the invention.
 - f. The Institution or Investigator or its licensee will use commercially reasonable efforts to make MDA inventions available for the public benefit within a reasonable period of time. MDA shall have the right to notify Institution or Investigator in writing that it believes there has been an unreasonable delay in making the MDA invention available for the public benefit, and unless within sixty (60) days thereafter

Institution, Investigator or its licensee demonstrate to MDA's reasonable satisfaction that appropriate efforts are being made, MDA has the right, notwithstanding any exclusivity provisions of any license granted by Institution or Investigator, to grant a license with respect thereto to a party designated by MDA on such terms as are reasonable in the circumstances.

g. MDA shall have a perpetual, nonexclusive, nontransferable, irrevocable, fully paid, royalty-free and sublicensable right and license thereunder to practice for noncommercial research purposes only, all MDA inventions and patents filed or issued thereon of which Institution or Investigator retains ownership of in accordance with this Section 2.

h. Any licenses or transfers of any patent applications, patents, know-how or other rights in an MDA invention shall be subject to the rights of MDA under this Patents and Licensing Policy.

3. If the Institution or Investigator has no patent or licensing policy and procedure for administering inventions, MDA shall have the right to determine the disposition of the invention rights in any such case.

Exhibit 2:

Translational Research Grants Communications and Confidentiality Policy

By accepting an MDA award for a research project, the company Principal Investigator or other personnel contributing to and working on the Project, as well as the Institution(s) or companies with which they collaborate, agree to be bound by the terms and conditions of MDA's Translational Research Grant Communications and Confidentiality Policy as they relate to the project for which the grant has been awarded. MDA in turn agrees to abide by the same provisions described in this policy. Additional provisions may be negotiated during the period before the recipient company formally accepts the MDA award. MUSCULAR DYSTROPHY ASSOCIATION, INC. ("MDA") understands that information is sensitive and its release can be harmful to certain entities, and that proprietary information needs to remain confidential and protected. In turn, the recipient company or institution recognizes that dissemination of information about MDA funded research projects is important to the Muscular Dystrophy Association and the families that it serves. Such information is critical to ensuring the continued financial support of the Association by the public. If the recipient company or institution has an established confidentiality agreement that is known to and accepted by MDA, MDA may choose to accept, in addition, those terms of that policy or agreement that do not violate or supersede those of MDA's Translational Research Grant Communications and Confidentiality Policy.

Policy Terms:

1. MDA retains the right to make public the title and amount of all funded projects, as well as a brief lay summary. All other project-related information, including the substance of the grant application, any resulting progress reports, or other written or oral communications is considered confidential and will not be released to other than MDA staff without specific, written permission from the recipient company or institution. Recipient companies/ institutions should designate one representative (project information officer) to oversee and authorize release of project-related information.
2. It is understood that MDA and the recipient company or institution will make every effort to coordinate publicity related to work funded by MDA, and that MDA will respect confidentiality agreements and proprietary information about this work. All press releases or other information designated for public release that is related to the awarded project, whether generated by MDA or the recipient company, must be reviewed and approved by both the recipient company and MDA. Company-generated press releases and journal publications should include a reference to the support received by the Muscular Dystrophy Association and its role in the research project. Conversely, press releases and other public media generated by MDA will acknowledge the recipient company or institution by name.
3. Any and all project-related outcomes, achievements must be reported to MDA as specified in the grant paperwork as part of milestone and progress reports.
4. Copies of any papers resulting from an MDA research award must be sent to the MDA Research Department upon acceptance for publication, even if the publication date is several months away, or if there is no publication date known. Journal embargoes will not be violated.
5. Failure to adhere to this policy will result in termination of project support.