



INTERNATIONAL RETT SYNDROME FOUNDATION POLICY STATEMENT ON RESEARCH SUPPORT

Research Awards/Post-Doctoral Fellowships

All Awards funded by the International Rett Syndrome Foundation (IRSF) are subject to the terms and conditions outlined in this Policy Statement. Deviations from the policies outlined in this document are valid only if made in writing and signed by the Chief Scientific Officer of IRSF. All research undertaken with IRSF funding is the sole responsibility of the Principal Investigator of that grant. The Principal Investigator and Sponsoring Institution are both responsible for insuring that all research activities are conducted in a safe, responsible and ethical manner.

Grant Period and Payments

Investigators may request support for up to a two-year period but Awards made by IRSF are usually funded one year at a time. Although IRSF intends to fund the second year of two-year Awards, the Principal Investigator acknowledges that the second year of funding, if any, requested in his/her initial application is contingent on the timely submission of a non-competitive progress report, satisfactory to IRSF, as well as on the availability of funding to IRSF. The funding period for each project commences on October 1st unless IRSF's Chief Scientific Officer has notified the Principal Investigator of an alternate commencement date. All grant payments are made quarterly.

Research Proposal

The Principal Investigator shall commence the research described in the Research Proposal on or about the time that the first grant payment is received by the Sponsoring Institution. If the Principal Investigator is unable to commence the project at that time, the Chief Scientific Officer of IRSF should be promptly notified and IRSF may, in its discretion, choose to terminate the grant. Funds provided by this grant are for the purposes of conducting the research described in the Research Proposal and may not be used for any other purpose without the express written consent of IRSF's Chief Scientific Officer. When applicable, an



amount no more than 10% of the direct costs allocated for the Research Proposal shall be used for indirect (Sponsoring Institution's overhead) costs. Allowable expenses by category shall be as specified in the Grant Award letter accompanying the statement of Terms and Conditions. Funds that are unexpended or uncommitted at the termination of the grant shall be remitted to IRSF within sixty days.

Progress and Financial Reports

Award recipients must provide IRSF with a brief narrative 6-month progress report due **March 15th** of the year following commencement of the Award. Second year funding of two-year awards is contingent upon the timely submission of a non-competitive scientific year-end progress report satisfactory to IRSF. This report is due no later than **August 15th** of the year following commencement of the Award and shall delineate the objectives and accomplishments of the project to date. The progress report shall also highlight unanticipated problems or substantial deviations from the research timetable outlined in the original Research Proposal. An interim financial report signed by the responsible administrative official at the Sponsoring Institution should accompany the year-end progress report.

A second interim scientific progress report is due no later than **March 15th** of the second year of the Award and shall delineate the objectives and accomplishments of the project since the year-end report.

The Principal Investigator shall be responsible for submitting a Final Progress Report to IRSF no later than **November 30th** or sixty days after the termination of the grant. The Final Progress Report should delineate (a) the objectives and significant findings of the research, (b) future directions suggested by the research, (c) if a proposal based on the IRSF-funded research is being submitted to the NIH or other entity for additional funding, and (d) a listing of publications in preparation, submitted or in press stemming from the research. A Final Report of Expenditures signed by the responsible administrative official at the Sponsoring Institution should accompany the Final Progress Report along with the unexpended balance of awarded IRSF funds. The Principal Investigator should be aware that IRSF may use all or portions of the Final Progress Report for publicity purposes such as a report in its newsletter and other publications.

Templates for scientific and financial reports are available on our website under "For Funded Investigators": <http://www.rettsyndrome.org>



Publication Policy

It is expected that the results of research supported by IRSF will be published as rapidly as possible in the open literature, consistent with high standards of scientific excellence and rigor. The responsibility for publication lies exclusively with the Principal Investigator and results of any work supported through IRSF may be published without prior review by IRSF.

Any publication arising in whole or in part from an Award funded by IRSF shall acknowledge funding support by IRSF. As soon as a manuscript is accepted for publication (whether during the term of the Award or after it has terminated) a copy of the publication along with the name of the journal and expected date of publication should be forwarded to IRSF's Chief Scientific Officer. As soon as reprints are available two copies of the reprint should be forwarded to IRSF's New York office.

Sharing Policy

IRSF-funded investigators shall be required to make reagents (i.e. animal models, expression plasmids, antibodies, permanent cell lines) and detailed protocols for their use available, upon request, to qualified scientists. Protocols will also be included on the IRSF website. Recipients will be expected to bear shipping costs and acknowledge the source of the reagents in resulting publications.

Rett Syndrome Symposium

IRSF-funded researchers are required to attend the annual Rett Syndrome Symposium. In the second year of funding award recipients are expected to submit an abstract.

Patent Policy

Discoveries and related regulatory approvals made under IRSF's sponsorship are the property of the Sponsoring Institution or Principal Investigator conducting the research; *provided, however*, that IRSF shall have the right of royalty-free use for noncommercial purposes of such discoveries. The Sponsoring Institution and Principal Investigator are responsible for insuring that prompt public disclosure of all commercially usable information is made as soon as practical. The Principal



Investigator and Sponsoring Institution are also responsible for notifying IRSF of the filing of any letters patent for any discovery made on research funded by IRSF.

Termination of the Award

This Award may be terminated or cancelled by IRSF upon 30 days written notice to the Principal Investigator and Responsible Administrative Official at the Sponsoring Institution if, in the sole discretion of IRSF, (a) the Principal Investigator is unable to carry out, in a timely manner, the research for any reason, (b) the Principal Investigator or any member of his/her research team is found by an institutional investigation to have committed scientific misconduct or fraud, (c) the Principal Investigator has failed to comply with any of the terms and conditions of this Award or (d) IRSF concludes that the Principal Investigator has received overlap funding for the Award or that the funds are not being used for the purposes originally outlined in the Research Proposal. In the event of cancellation or termination, all unexpended funds as of the termination/cancellation date must be returned to IRSF within 45 days of such written notice.

The Principal Investigator and Sponsoring Institution are responsible for notifying IRSF immediately and in writing of any institutional investigation into the conduct of the Principal Investigator or any member of his/her research team and for keeping IRSF informed on a timely basis of the progress and outcome of the investigation.

Transfer or Retirement of the Principal Investigator

If prior to the termination of the grant, the Principal Investigator's employment, affiliation or other relationship with the Sponsoring Institution is terminated for any reason, the grant will be terminated and all unexpended or uncommitted funds shall be returned to IRSF within 45 days. Awards may not be transferred to another individual working at the Sponsoring Institution nor transferred to any other institution without the prior written consent of IRSF's Chief Scientific Officer.

Ownership of Equipment

Title to all equipment purchased with IRSF funds shall vest in IRSF for the duration of the Award and for a period not to exceed sixty days from the



termination date of the Award. During this time, IRSF may, at its option, direct the transfer of title to the equipment to the Sponsoring Institution, Principal Investigator or to a third party. After such time, title to the equipment shall revert to the Sponsoring Institution.

Indemnification

The Sponsoring Institution agrees to defend, indemnify and hold IRSF, its officers, trustees, employees and agents harmless from and against any and all damages, claims, liabilities or demands which may be made or asserted by reason of: (a) any injury or loss to persons or property sustained for whatever reason whatsoever by the Sponsoring Institution, Principal Investigator or its or their officers, employees, agents, subcontractors, patients, visitors or other individuals who may be involved in the research outlined in the Research Application, and (b) any injury or loss to persons or property sustained for any reason whatsoever by any person caused by or otherwise attributable to acts of omission or commission of persons performing work pursuant to the research project.

Human Subjects

For research involving human subjects, the Sponsoring Institution shall ensure that the research proposal is reviewed and approved in writing by an Institutional Review Board constituted in accordance with current regulations promulgated by the United States Department of Health and Human Services and approved by the Department. Legally acceptable consent must be secured for all human subjects taking part in any research funded in whole or in part by IRSF. IRB approval forms from an Institutional Review Board must be submitted for the life of the grant (whether granted for its entirety from the outset, or renewed during the grant.)

Use of Experimental Animals

For research involving animals, the Sponsoring Institution shall ensure compliance with applicable chapters of the Public Health Service Animal Welfare Policy, the NIH Manual for Grants and Contracts, and any and all requirements of the Sponsoring Institution concerning animal welfare. Approval forms from the Sponsoring Institution's Animal Welfare Committee must be submitted for the life of the grant (whether granted for its entirety from the outset, or renewed during the grant.)



Overlap Funding

The Principal Investigator and the Sponsoring Institution are responsible for ensuring that the research described in the Research Proposal is not sponsored or funded by any other entity or organization. If support for the project is obtained elsewhere, the Principal Investigator agrees to notify IRSF promptly. Any funds awarded by IRSF may be withdrawn should funding be received for the same purposes from other sources.

Laboratory Visits

As a condition of support, the Principal Investigator agrees that a representative of IRSF may visit the laboratory where the grant is being funded upon reasonable prior notification.

Notices

Any notices or other communications among IRSF, the Principal Investigator and the Sponsoring Institution shall be sent by US Mail, certified mail, return receipt requested, or by overnight courier, and addressed to IRSF, 3 Columbus Circle, Suite 433, New York, NY 10019 and to the Principal Investigator and the Sponsoring Institution at such address as appeared on the Research Proposal submitted to IRSF or to such other address as shall have been specified in writing to the other parties and delivered in accordance with this section.

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