

Benign Essential Blepharospasm Research Foundation

Research Funding Terms and Conditions

As used in these Instructions and in the Terms and Conditions, "Grant" means any type of funding received from the Benign Essential Blepharospasm Research Foundation (BEBRF), including without limitation, from Research Grants, Fellowships, or other Awards.

Eligibility

The applicant seeking Foundation funding must be employed at a for-profit or non-profit organization or institution (each referred to as a "Grantee Institution") within the United States, Canada, or those foreign countries where supervision of grant administration is possible. Such Grantee Institution must agree to be bound by these Terms and Conditions by signing this Application through its duly authorized representative. If the Grant Application is approved, the Grantee Institution will be the direct payee of the Foundation's funding and receive such funding on behalf of the Recipient and will be solely responsible for the handling and disbursing of such funds in support of the Recipient's research.

Award Process

Applications will be reviewed by the Benign Essential Blepharospasm Research Foundation's Medical Advisory Board (MAB) for managing the grant process (referred to as the "MAB"). The MAB will evaluate and rank the proposals on the basis of scientific merit, relevancy, and other factors as determined by the MAB, in its sole discretion, and will make recommendations to the Foundation. The Foundation will make the final award decisions, in its sole discretion.

Disbursements

Any funds awarded will be disbursed in one lump sum upon approval of a Grant. The disbursement is subject to the availability of funds, to the Recipient's satisfactory progress as determined by the Foundation in its sole discretion (such progress to be detailed by the Recipient in a series of required Progress Reports as defined and described in the Terms and Conditions) and to the further requirements and limitations set forth in the Terms and Conditions. As used in these Instructions and in the Terms and Conditions, "Recipient" means the recipient of any Grant.

Public Relations

The Recipient of any Research Grant, Fellowship or other Foundation Award agrees to the announcement of such award in media chosen by the Foundation, and will provide a recent photograph of himself/herself for publication in the BEBRF newsletter, on the Foundation's website, or elsewhere as desired by the Foundation. Recipient will also provide the name of a contact within their institution's Public Relations department so that the Foundation can coordinate the release of PR around the issuance of the Grant.

Resources

Tissue samples, cell lines and reagents related to blepharospasm previously collected or developed by Foundation-funded investigators may be made available to other investigators through the Foundation solely for non-commercial research purposes. Brain tissue from blepharospasm patients may also be requested from a brain tissue repository.

Human Subject Protection

For all investigations involving human subjects, approval by the Grantee Institution's human investigation committee is mandatory.

Benign Essential Blepharospasm Research Foundation

Research Funding Terms and Conditions

Recombinant DNA Research and Animal Welfare

The regulations pertaining to these two areas as established by U.S. Public Health Service have been fully adopted by the Foundation and are incorporated herein by reference, and Recipients are hereby charged with knowledge thereof and bound to the obligations therein.

Conditions of Award

Publication and Sharing of Research Results

The Foundation expects that all Recipients will publish all meaningful results and findings of his/her work in peer-reviewed scientific journals in an expeditious manner. Future funding of Recipient may in part be influenced by the extent to which the Recipient complies with the foregoing. All results and findings of Recipient's work that are not published or otherwise disclosed to the public within one year after the end of the grant period will be provided by Recipient to the Foundation, and the Foundation may publish, disclose, and use such results and findings without limitation in its sole discretion. Recipient will acknowledge the Foundation on any published or distributed work or audiovisual results or findings of work supported in whole or in part by the Foundation. In addition, any publication(s) in the peer-reviewed literature that results from work supported in whole or in part by the Foundation must be reported to the Foundation and five (5) copies of any reprints of such publications must be sent to the Foundation office.

Limited availability of research results or resources impedes the advancement of science. In addition to the Foundation's own policies, the Foundation subscribes to the NIH policy on sharing data and resources as explained in the Federal Register, Vol.64, No.246, December 23, 1999; provided that, in the event of conflict, the Foundation's policies will control. Research tools and other materials developed by the Recipient with Foundation support must be made available by the Recipient and the Grantee Institution for noncommercial research purposes to other investigators, including on a non-collaborative basis, within one year after the final working day on the Grant, or immediately after acceptance of results or findings for publication, whichever occurs first. All applicants must include a description of a specific plan for sharing and distributing such tools and materials so that other researchers can benefit from these resources, or state reasons why such sharing is restricted or impossible. Notwithstanding an applicant's stated reasons for why sharing of tools and materials should be restricted or is impossible, the Foundation reserves the right to require sharing and distributing such tools and materials. Categories of these resources include but are not limited to chemical compounds, organisms (including animal models), reagents, cell lines, viruses, cell products, cloned DNA, DNA sequences, genetic mapping information, and crystallographic coordinates.

Progress Reports

The disbursement of any funding awarded pursuant to a Grant requires the Recipient's demonstration of progress that is satisfactory to the Foundation, in its sole discretion. Recipient will be required to submit written reports to the Foundation from time to time as follows describing progress made on research ("Progress Reports"). Recipient will submit a short Progress Report due 5-½ months after receipt of funding ("Initial Progress Report"). The Initial Progress Report will be no more than one page and should focus on progress made toward meeting the milestones outlined in the approved Grant Application. The Recipient will also submit a detailed Progress Report at nine months after receipt of funding and at 18 months for two year grants ("Interim Progress Reports"). Recipient's final Progress Report must be submitted within 5 months after the end of Recipient's last day to work on the Grant ("Final Progress Report"). All Interim Progress Reports and the Final Progress Report must include information as to whether the funded project has achieved the specific milestones, aims, and

Benign Essential Blepharospasm Research Foundation

Research Funding Terms and Conditions

objectives included in this Grant Application, as well as a brief lay summary suitable for publication in the Foundation newsletter. The Final Progress Report must also include a plan for publication of results and findings within one year after the end of the grant period. At the Foundation's request, Recipients will also make a presentation about the significance and progress of their work to a meeting of the Committee and any other participants chosen by the Foundation. Upon reasonable notice, Grantee Institution and Recipient agree to allow representatives of the Foundation to visit the Recipient's facilities where the research is being conducted in order to gain further knowledge to evaluate Recipient's progress.

Recipient will notify the Foundation in writing immediately if the Recipient changes institutions or discontinues work on the funded research. If the Recipient fails to perform the work in good faith according to this Grant Application, the Recipient and the Grantee Institution agree to return unused funds upon request by the Foundation. The Recipient may submit a letter of explanation and a revised Grant Application for reinstatement of funding which will be reviewed by the Committee and the Foundation. Recipient will provide the name of the Grantee Institution or institutions to whom the funding checks are to be made payable and indicate where the checks are to be sent.

Duplication of Support

The Recipient and Grantee Institution hereby assure the Foundation that this project is not receiving, and will not receive, other funds to support any part of it. In the event that the Recipient is currently funded, expects to be funded in the future or has applied for funding from other sources, Recipient must disclose all other sources of funding. After beginning the project, any funding received by the Recipient that will be used to support any research that is being supported by the Foundation must be disclosed as soon as the new funding has been approved. Under any circumstances where there is or has been duplication of support, the Foundation reserves the right to alter or suspend further support of all parts of the project and request repayment of duplicated funds.

Inventions, Patents and Public Access

All Grants are subject to the Foundation's policies on Inventions and patents described herein. By returning an executed copy of this Grant Application, if a Grant is awarded, the Recipient and the Grantee Institution(s) with which he/she is affiliated agree to be bound by the following terms and conditions on Inventions and Patents, and further agree to bind all his/her and its employees, agents and representatives performing work in connection with the Grant by such terms and conditions.

1. As used in these Terms and Conditions, "Invention" shall mean all inventions, products or processes, innovations, discoveries, findings and improvements (whether or not patentable), research tools and other materials discovered, conceived or first reduced to practice in the performance of research supported in whole or in part by the Foundation.

2. Upon discovery of any Invention, Recipient must report such discovery to the Foundation in the next Progress Report due hereunder. Recipient must also promptly (but in no event later than 30 days thereafter) notify the Foundation in writing of the filing of any patent application for an Invention and of any patent that has been issued in any jurisdiction. Recipient must notify the Foundation prior to its or the Grantee Institution's execution of any license or other agreement concerning an Invention.

Benign Essential Blepharospasm Research Foundation

Research Funding Terms and Conditions

3. Unless otherwise provided herein, the Grantee Institution will own all Inventions and will not transfer ownership in whole or in part to any third party other than a transfer or license to the United States government, if required by law.

4. If results or materials generated with Foundation funding (in whole or in part) lead to patent issuance, licensing, commercialization, or otherwise generate revenues for the Recipient or Grantee Institution, the Recipient or Grantee Institution, as the case may be, will pay royalties to the Foundation in accordance with terms to be negotiated in good faith between the parties. The parties agree that their goal in establishing the rate of royalties shall be at a minimum to enable the Foundation to recoup its contribution. Such royalties shall reasonably reflect the proportion of the total funding for research provided by the Foundation. In the event that there are other sources of funding, the Recipient, the Grantee Institution and such other funding sources shall negotiate the appropriate royalties to be paid to the Foundation subject to the aforementioned guidelines. Such terms shall otherwise be in accordance with prevailing industry practice.

5. Neither Grantee Institution nor Recipient will enter into any agreement that conflicts with their respective obligations under these Terms and Conditions and each shall ensure that its employees, agents and representatives do not enter into any such agreement. If Recipient or Grantee Institution licenses or otherwise grants rights to an Invention to any party, it will require a written agreement that requires such party to; (i) include provisions in the agreement obligating the other party to commercialize the Invention in a diligent manner to ensure its Practical Application (as described below); (ii) include appropriate diligence requirements and milestones; and (iii) monitor the performance of the other party.

6. An objective of the Foundation in awarding Grants is to bring inventions to Practical Application as expeditiously as possible. In furtherance of this objective, if Recipient or Grantee Institution (or any of its licensees) has not, within two years of notifying the Foundation of an Invention as required herein, taken effective steps to bring the Invention to Practical Application, or has discontinued efforts to bring the Invention to Practical Application, at the Foundation's request, the Recipient and Grantee Institution will: (i) assign said Invention and all associated patents and other intellectual property rights to the Foundation; (ii) cancel any outstanding exclusive and non-exclusive licenses; (iii) grant exclusive or non-exclusive licenses to said Invention, as directed by the Foundation; or (iv) make any other reasonable disposition of the Invention, as directed by the Foundation. As used herein, the term "Practical Application" means to utilize and commercialize an Invention in such manner as to ensure that its benefits are, to the extent permitted by law or government regulations, widely available to the public on reasonable terms.

Dispute Resolution

In the event that a dispute arises concerning the terms of this Grant Application and cannot be resolved through negotiation between the parties, both parties agree to seek binding arbitration as the exclusive means to resolve such a dispute. Arbitration shall be administered by the American Arbitration Association under its Commercial Arbitration Rules, and judgment on the award rendered by the arbitrator(s) may be entered in any court having jurisdiction thereof.

Other Terms

All rights and responsibilities set forth in the Instructions are hereby incorporated by reference into these Terms and Conditions. These Terms and Conditions constitute the entire agreement among the

Benign Essential Blepharospasm Research Foundation

Research Funding Terms and Conditions

Foundation, Recipient and the Grantee Institution. Nothing contained in any documents or information provided by Recipient or Grantee Institution in completing this Grant Application, in any progress report or in any other documentation or information provided by Recipient or Grantee Institution shall modify these Terms and Conditions, unless such modification is specifically acknowledged and agreed to in writing and signed by the Foundation.

Agreed and Acknowledged

By signing below, Recipient and Grantee Institution agree to be bound by the Terms and Conditions of this Grant Application:

By: _____
Print Name of Principal Investigator

Signature of Principal Investigator Date

By: _____
Print Name of Grantee Institution

Print Name and Title of Grantee Institution's authorized representative

Signature of Grantee Institution's authorized representative Date