



## **Scientific and Medical Research Grant Guidelines and Policies**

*(Last revised June 2015)*

The guidelines below summarize the guidelines and policies of EB Research Partnership (“EBRP”) regarding scientific and medical research grants.

### **I. Statement of Purpose**

Epidermolysis Bullosa, commonly known as EB, is a group of life-threatening genetic skin conditions that affect children from birth. EBRP awards grants on a competitive basis to qualified applicants who seek to conduct scientific and medical research (including research-enabling projects) that will lead directly to commercially feasible products and therapies and infrastructure or tools needed to support commercially feasible products and therapies for treating and/or curing EB. As further discussed below, EBRP awards grants under a venture philanthropy framework whenever possible.

### **II. General Guidelines**

The following general guidelines apply to EBRP research grants:

- A. Except with the approval of the Executive Committee of EBRP’s Board of Trustees, each principal investigator must hold (i) a medical degree and/or a doctoral degree in a relevant field and (ii) a post-doctoral or faculty position (or beyond) at a university, medical school or other institution that regularly hosts scientific and/or medical research.
- B. Except with the approval of the Executive Committee of EBRP’s Board of Trustees, EBRP will grant awards only to applicants affiliated with institutions with 501(c)(3) status (or the equivalent for foreign institutions). Any grants made to for-profit entities will employ a venture philanthropy framework; no exceptions will be made.
- C. EBRP awards grants on the basis of the proposed project, as well as the principal investigator(s) and sponsoring institution(s). Permission for any change in the principal investigator(s) and/or sponsoring institution(s) must be approved in writing by EBRP. If a principal investigator terminates his/her affiliation with the sponsoring institution identified in the grant contract and wishes to continue the project at another qualified sponsoring institution, the principal investigator must promptly (and in any event within 45 days) notify EBRP in writing. EBRP reserves the right to require resubmission of any or all grant application materials with appropriate changes, including, but not limited to, venue and staffing, and EBRP reserves the right to reject any such changes, in whole or in part.

### **III. Use of Grant Funds**

- A. Except as otherwise set forth in the grant contract, EBRP will disburse grant funds on a quarterly basis. EBRP reserves the right to withhold disbursement of grant funds at any time pending resolution of a dispute with respect to the use of funds, the project budget and milestones and/or the applicant's satisfaction of any conditions and requirements of the grant.
- B. A maximum of five percent (5%) of grant funds may be allocated to indirect costs. Upon request EBRP will provide a letter to the sponsoring institution confirming the policy adopted by EBRP's board of directors regarding indirect costs.
- C. EBRP grant funds may be used only for the specific use(s) set forth in the grant contract. Except with the express written permission of EBRP, any funds not used during the grant period for the specific use(s) set forth in the grant contract must be returned to EBRP promptly following the end of the grant period.
- D. Except as otherwise set forth in the grant contract, EBRP grant funds may not be (i) contributed to a unified or pooled fund that will be used to award grants or support other projects or (ii) used for any of the following:
  - a. (a) salaries, benefits and/or stipends for persons not specifically identified in the grant contract;
  - b. (b) general institutional expenses;
  - c. (c) general fundraising expenses; and
  - d. (d) journal subscriptions, advertisements, tuition fees, professional society dues; and
  - e. (e) travel and related expenses (except to the extent travel pertaining to study participants is included in the approved grant budget), meals or entertainment.

### **IV. Grant Applications**

EBRP's grant application requirements and procedures for the current funding cycle can be found on EBRP's website (<http://ebresearch.org/research/>). Grant application materials will be evaluated by EBRP (including, if appropriate, EBRP's Scientific Advisory Board). EBRP expects to evaluate grant applications for future funding cycles on a semi-annual basis.

### **V. Venture Philanthropy**

In order to magnify the impact of the research dollars funded by EBRP and its donors and to create a more sustainable philanthropic model, EBRP adopts applicable concepts from venture capital investing and applies them towards achieving its goals of treating and curing EB – a model EBRP refers to as “venture philanthropy.” Specifically, when commercially successful treatments and therapies are developed with EBRP grant funds, EBRP expects to participate financially via revenue or royalty share, guaranteed ROI, warrants, equity, or other means. EBRP re-deploys any financial gain received into funding additional EB research. EBRP believes that the venture philanthropy approach aligns incentives among all parties involved and

enables EBRP to fund larger, multi-year projects with the goals of “de-risking the science” and, in turn, attracting investments by commercial partners.

As EBRP considers grant applications, it evaluates the commercialization potential of proposed projects and projected economic returns to EBRP. Prior to receiving EBRP grant funding, applicants and their affiliated institutions will be expected to negotiate in good faith regarding EBRP’s financial participation, as well as patent and intellectual property management, technology transfer and related issues (collectively, “Commercial Matters”). Agreements reached regarding Commercial Matters will be memorialized either in the grant contract or a separate agreement entered into between the relevant parties.

## **VI. Additional Responsibilities of Grant Recipients**

- A. Unless alternative reporting requirements are set forth in the grant contract, principal investigators receiving grant funds from EBRP are required on an annual basis (or more frequently upon thirty (30) days’ request by EBRP) to submit a reasonably detailed project update report and an accounting of all grant funds expended, as well as to submit a final accounting and progress report within sixty (60) days of the end of the grant period.
- B. EBRP expects that the knowledge resulting from research funded, in whole or in part, by EBRP will be promptly and broadly disseminated through appropriate scientific channels. If research results are to be published, EBRP should receive written notice at least ten (10) days (or otherwise, as soon as practicable) prior to publication, including a PDF of the article and any press releases related thereto. Except with the written permission of the principal investigator(s), EBRP will not publicly disclose such information until the article has been published. Publications of or relating to EBRP-funded research should bear the statement: “THIS WORK WAS SUPPORTED BY A GRANT FROM EB RESEARCH PARTNERSHIP.”
- C. EBRP’s prior written approval is required for all public and/or media communications relating to an EBRP grant. Except as required by applicable law or the policies of the sponsoring institution, or with the written permission of EBRP, neither the applicant nor the sponsoring institution may publicly disclose the amount, terms and conditions of the award.
- D. EBRP will not be responsible for any claim, judgment, award, damages, settlement, negligence or malpractice arising from the research or investigation funded by EBRP or otherwise related to EBRP-funded research or investigation. The principal investigator(s) and the sponsoring institution(s), for itself and on behalf of its employees, agents, or representatives, must release EBRP and its officers, directors, employees and representatives from any such claim, judgment, award, damages, settlement, negligence or malpractice.