

DEBRA Australia Ltd Research Grant Application Guidelines, Terms and Conditions

1. CALL FOR APPLICATIONS

DEBRA Australia is pleased to call for applications for new research funding for projects aimed at improving the health and wellbeing of children and adults with Epidermolysis Bullosa (EB), in any of DEBRA's priority research areas. The deadline for application submission is **31 October 2018**. Two grants of up to AUD \$40,000 each over 1 year are being offered. Depending on the applications received, the total grant money may be split into three smaller awards. It is planned that decisions on funding applications from this call will be made in December 2018.

Projects may be laboratory based, a clinical study, or a combination. As DEBRA Australia is keen to create a more robust and collaborative EB research environment in Australia, projects which involve Australian or international collaboration are encouraged. Projects are expected to be completed by December 2019 with respective progress and final reports to DEBRA Australia due in July 2019 and January 2020. Grants will be paid in two equal instalments in January 2019 and July 2019 (following assessment of progress report), on receipt of an invoice from the institution.

Applicants are strongly encouraged to study these guidelines, terms and conditions carefully before preparing their application.

Our Research Priorities, which are aligned with the priorities of DEBRA International, are:

- Improve our understanding of the biology and genetics of all forms of EB, as better understanding can lead to new approaches to diagnose and treat EB.
- Work towards the development of therapies (including possible gene-therapies, cell-therapies, drug therapies or protein therapies).
- Understand the nature of wound healing and the development of skin cancer in EB, and seek to develop better treatments and prevention strategies.
- Support clinical-care research to improve the management of EB through symptom relief.

2. APPLICATION GUIDELINES

2.1 Format & Submission: Applications shall follow DEBRA Australia's application format, using the form available from DEBRA Australia's office (secretary@debra.org.au) or website (www.debra.org.au).

Applications must be prepared using Arial font, size 11, with standard margins of 2.5cm, and stapled. Applications that do not conform to the guidelines or to instructions in the application form will NOT be accepted.

Print one (1) FULL copy along with any supporting documentation, and mail to DEBRA Australia PO Box 226 PITTSWORTH QLD 4356. One electronic copy of the application in PDF format directly converted from the word document (signatures are not required on the PFD version) should be emailed to secretary@debra.org.au.

NB: Late applications will NOT be accepted.

2.2 Project size and scope: This application may relate to a novel small research project that may be a part of the larger project that applicants are undertaking, or a new small pilot project. Applicants must be realistic about the amount of work that can be achieved in the time frame and within the budget requested. DEBRA cannot provide funding for projects that overall have insufficient funding or resources. Applicants are asked to provide details of other funding and infrastructure that will be available to them in order to ensure the project can be completed successfully. Applicants must demonstrate funding from other sources for other aspects of a larger project. Funding will be for a 12 month period only. Requests for funding for longer periods will not be considered.

One application ONLY per Principal Investigator will be considered. However, other researchers in a group may apply for a grant in their own right as chief investigator.

2.3 Project Description: The aims and objectives of the proposal should be clearly stated in the light of existing knowledge of the subject area. Similarly, relevant hypotheses will be judged in relation to the description of other research. The description of the methods should be concise, yet contain sufficient information to enable the reviewers to judge the feasibility and appropriateness of the project in relation to its objectives or hypotheses. Evidence will also be sought to ensure that the applicants will be able to establish the methods for their research. Experimental design will be scrutinised to ensure that it is based on sound statistical principles. Any statistical method used in preparation of the application should be detailed. Statistical methods not commonly used should be supported by references. Key activities and milestones must be outlined in the application form to enable evaluation of the achievement of these milestones at each reporting period.

2.4 Impact on EB: The application must clearly explain how the proposed project fits with Debra's research priorities and the potential impact on the health and wellbeing of children and adults with Epidermolysis Bullosa (EB).

2.5 Personnel: The grant applicant is expected to be of sufficient seniority and experience to manage the project. An estimate of time to be spent on the project by the PI and other participants must be given, plus any anticipated significant absences of senior investigators during the grant period.

2.6 Eligibility for salary support: DEBRA will not normally fund any part of the salary of the Principal Investigator (PI) or other senior investigators, as it is assumed that they will already have a guaranteed position for at least the length of time covered by the grant application. The grant may be used to part-fund junior and technical personnel, but other sources of funding must also be declared.

2.7 Other eligible expenditure: DEBRA will fund research consumables, expenses and the purchase of special equipment associated solely with the grant application, as detailed in DEBRA's formal offer of the grant. It is not the policy of the committee to recommend funding

for items which might normally be expected to be provided by the organisation's allocation for goods and services. Institutional or administration levies will not be funded. Travel expenses, including attendance at meetings or conferences cannot be met from the grant.

2.8 Related grants: All applicants will be required to supply information regarding current external grants held and applications pending which are relevant to the application. DEBRA will not fund projects that form part of the core activity of another funded grant. Projects which have received funding from DEBRA International may receive top-up funding from DEBRA Australia for an additional element of the project. Normally a project already receiving external funding will not be recommended for funding by DEBRA. However special consideration may be requested if the other grant is far smaller than that being requested from DEBRA. Nevertheless, applicants are encouraged and expected to seek funds elsewhere wherever possible. If other funding is successfully obtained for a project that is funded by DEBRA, then DEBRA's funding will be withdrawn and reallocated to another fundable project as appropriate.

2.9 Institutional approvals: Project proposals must include the support of the relevant Department Head and evidence of submission to appropriate institutional committees such as Ethics or Biosafety Committees.

2.10 Outstanding reports or funds: If the Chief Investigator has any outstanding reports or funds not expended from a previous DEBRA Australia or International research project grant, these must be finalised prior to making an application for the current funding round. Failure to do so may make the applicant ineligible for future funding.

2.11 Review of Applications: Each application will be subjected to a careful review by the Research Committee which will submit its recommendations to the DEBRA Australia Board. Reports from up to three external referees appointed by the Research Grants Committee will be taken into account. Applicants may request in writing that a certain individual NOT be contacted as a referee for their application, however the Research Committee will make the final decision about this. The Board's decision on the awarding of Research Grants will be regarded as final and the Board will not enter into discussion with unsuccessful applicants.

The Research Grants Committee and the external reviewers will take into consideration the following in reviewing the applications:

- Scientific quality (excellence of the research grant application).
- Significance and innovation.
- Track record of the applicant and team, relative to opportunity.
- Appropriateness of proposed budget including value for money.
- Timeframe and feasibility of achieving outcomes .

3. TERMS AND CONDITIONS FOR RESEARCH GRANTS

3.1 If you receive project grant funds from DEBRA which are, in part or in whole, received by us from another source, which has its own additional reporting requirements, this will be made clear to you at the time of the grant offer. Acceptance of the grant offer means that you agree to meet these requirements, too.

3.2 In the extreme cases of contemporaneous research developments negating the meaningful conclusion of the research, or where DEBRA's financial position is such that funding of the grant cannot be continued for the full term, DEBRA reserves the right to discontinue the grant by giving three months' notice of the intention to do so.

3.3 It is DEBRA's policy to publicise as widely as possible its grants and the scientific progress achieved through them. It is a condition of accepting financial assistance that grant holders agree to co-operate in such publicity efforts.

3.4 DEBRA Australia must be notified as soon as is reasonably practicable of any potentially patentable discovery or invention arising from work supported in whole or in part by DEBRA funding. DEBRA's written consent must be obtained prior to any disclosure or publication in any form of material or details relating to any such invention or discovery.

3.5 DEBRA requires the findings of the research it funds in full or in part to be published promptly, but with due regard to protecting the intellectual property of research outputs. The support of DEBRA must be acknowledged in all publications or other public output arising from the work funded, whether written or oral (e.g. scientific or popular publications, press releases, conferences, seminars, etc.). DEBRA must be acknowledged explicitly as the sponsor or co-sponsor of the research.

3.6 The results of the research and any intellectual property rights subsisting in the results must not be licensed on an exclusive basis for the treatment, prevention or diagnosis of Epidermolysis Bullosa (the "Field") or assigned in whole or in part to any third party without the prior written consent of DEBRA. The grantee will ensure that all reasonable endeavours are used by the exclusive licensee or assignee to exploit the results and intellectual property rights subsisting in the results in the Field. If all reasonable endeavours are not used, the grantee must terminate or convert the licence to non-exclusive or procure the assignment or license back of the results and intellectual property to the grantee for exploitation in the Field.

3.7 DEBRA is entitled to receive a reasonable proportion of any financial benefit received by the grantee or its affiliates arising from exploitation of the results of the research supported by DEBRA and any intellectual property rights subsisting in the results. If the financial benefit received exceeds a value of AUD\$50,000, then the grantee shall promptly pay to DEBRA an amount negotiated in good faith by the parties and representing a reasonable proportion of any financial benefit received by the grantee or its affiliates.

3.8 Continuation of grants will depend upon receipt of a satisfactory interim report 6 months after the first payment is made and a final report at the end of the grant period. No payment of grant owing will be made until any outstanding report has been received and accepted by DEBRA. Reports will be circulated to the Debra Australia Board and may be shared with Debra International. The lay summary may be circulated to other grant holders, national EB Support Groups, and used in publicity and placed on the DEBRA website. If there is any reason why this should not occur with an individual report, please inform DEBRA at the time of submission.



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3.9 Receipts for expenditure incurred during the period should be provided with the reports. Funds unspent or uncommitted at the termination of the grant shall be returned to DEBRA within eight weeks unless the DEBRA Board otherwise approves.

3.10 Grants awarded by DEBRA are subject to the standard conditions of grant at the time the grant is awarded. DEBRA reserves the right to change conditions of grant from time to time.