

GUIDELINES FOR HAEMOPHILIA FOUNDATION AUSTRALIA (HFA) RESEARCH FUND AND INFORMATION FOR APPLICANTS

GUIDELINES

1. BACKGROUND

The fund was established in 1990 upon the recommendation of the HFA Medical Advisory Panel, a subcommittee of HFA until the Australian Haemophilia Centre Directors' Organisation (AHCDO) was established independently as an incorporated association in 2001. Distributions from the fund have been made since 1994. HFA may receive tax deductible donations and bequests directed to the fund, and the HFA Council may allocate other funds to the fund at its discretion. HFA may conduct special campaigns to raise funds for the fund.

2. PURPOSE OF THE FUND

- a) HFA has funds set aside to fund clinical, scientific or social research undertaken within Australian institutions, and/or in Australia on haemophilia, von Willebrand disease and/or other related bleeding disorders and the complications of bleeding disorders, including blood borne viruses.

3. THE OBJECTIVES OF THE FUND ARE TO:

- a) promote and support research on the causes and prevention of bleeding disorders and their complications
- b) support projects where results will directly assist or improve the treatment and care; and quality of life of people with bleeding disorders
- c) provide funds to not for profit organisations and/or institutions, including HFA for promoting and conducting research
- d) promote and support education, lectures, seminars, conferences and workshops that will advance, encourage and promote research into bleeding disorders.
- e) support and evaluate pilot projects designed to initiate new services or update existing services provided for people with bleeding disorders and their families.

4. FREQUENCY OF GRANTS

The HFA Council has decided to make a sum of \$20,000 available for one or two grants each year

5. GRANT APPLICATION PROCESS

- a) The HFA Council will determine the frequency and amount of research grants to be distributed.
- b) The HFA Council will establish the Haemophilia Foundation Research Committee (HFRC), "the Committee", as an advisory committee to recommend funding priorities, assess research proposals and make recommendations for funding.
- c) The HFA Executive Director will provide a secretariat for the Committee.

6. HAEMOPHILIA FOUNDATION RESEARCH COMMITTEE

- a) The Committee will usually comprise two (2) representatives of the Australian Haemophilia Centre Directors' Organisation, one (1) representative of the Australian Haemophilia Nurses' Group, one (1) representative of the Australia/New Zealand Haemophilia Counsellors' and Social Workers' Group, one (1) representative of the Australia and New Zealand Physiotherapy Haemophilia Group and one (1) representative of HFA Council.
- b) The Committee will set and use assessment criteria to evaluate applications.
- c) The Committee may refer to an external research assessor if further information and/or specialisation is required and when this occurs, all communication between the research assessor and the Haemophilia Foundation Research Fund Committee shall remain confidential.
- d) An applicant may be requested to attend an interview with the Committee if deemed to be required.
- e) The Committee will refer its recommendation/s to the HFA Council, or to a meeting of HFA Office Bearers for a final decision to be made.
- f) The decisions of the HFA Council shall be final and there will be no further engagement or appeal process with HFA, the Haemophilia Foundation's Research Committee or AHCDO.
- g) Reasons for decisions will not be given.

INFORMATION FOR APPLICANTS

1) GENERAL CONDITIONS

- a) Applicants must be Australian residents, hold appropriate and relevant qualifications, and have substantial experience and proven ability in research.
- b) Where the applicant is the member of the staff of an institution or organisation, the applicant must have written approval of the responsible officer of the institution or organisation. The responsible officer may be a registrar of a university, director of a research institution, or CEO of hospitals and other organisations.
- c) Where the applicant is a member of staff of an institution or organisation, all communication to and from the fund relating to applications for grants, the award of grants, conditions associated with grants and payment of grants, shall be through the responsible officer of the organisation or institution.
- d) The award of any Fund grant is subject to the formal acceptance of the grant and conditions associated with the grant by the recipient of the grant, the Head of Department where the work will be carried out, and the responsible officer of the institution or organisation.
- e) Applications to the fund which have previously been unsuccessful may be submitted for further funding rounds with clear indication that the same research application has been submitted before.
- f) All grants are subject to funds being available and the fund is not bound to make any awards in any calendar year.

2. ETHICS CONSIDERATION

Research projects must be compliant with the National Statement and all national policy for ethical practice as established by the National Health and Medical Research Council, and where human experimentation is proposed, certification of ethics approval from an appropriate body (an appropriate institutional or other ethics review committee) will be required before the funding will be paid.

3. PAYMENT OF GRANTS

- a) Grants will be paid as a fixed sum and for a specified period as outlined in the grant offer. There will be no variation to the amount during the period of research.
- b) Payment of money in respect of any grant shall be upon the terms and conditions specified in the grant. Where the applicant is a staff member, payment will be made to the institution or organisation. Payments through institutions or organisations shall be half-yearly, in advance or otherwise by agreement before the first payment. Applicants not associated with an organisation or institution may receive payments monthly in advance. A tax invoice must be provided before any payment will be made.
- c) A progress report must be provided before the second or further payments are made.
- d) A grant recipient may be required to attend an interview with the Committee if deemed to be required before the second payment is made.
- e) The fund must be notified immediately a grant recipient leaves an institution or organisation. When a recipient leaves before the expiration of that grant, the grant may be terminated or transferred at the discretion of the fund.
- f) Grants which have not been expended or committed by the recipient at the end of the specified period shall be refunded, except where the fund approves the money being carried forward.
- g) Grants will be used solely for the purpose for which they were approved. Failure to carry out the research project in the terms of the grant shall be a breach of conditions of the grant and the institution, organisation or individual shall be responsible for refunding part or all of the money already paid, and any further payments will be terminated.

- h) The grant will be terminated if in the opinion of HFA, the research for which the grant is approved is not being carried out with competence, diligence and scientific honesty.
- i) Each institution or organisation will undertake to provide all necessary overhead expenses and institutional or organisational maintenance charges, and no portion of the grant shall be applied to these purposes.
- j) Except as provided by the following clause, all taxes, duties and government charges imposed or levied in Australia or overseas in connection with the performance of this grant shall be borne by the institution or organisation.
- k) The grant payable will include a GST component to cover liability for Goods and Services tax ("GST"). A tax invoice must be issued by the grantee to the fund.
- l) The grant recipient shall be responsible for seeking all required regulatory approvals for any equipment or materials purchased outside Australia.
- m) Any discovery arising out of research projects supported by the fund shall not be the subject of an application for patents without the prior written approval of HFA and the agreement of the institution or organisation in which the work is carried out.
- n) Intellectual property resulting from funded research usually belongs to the institution or organisation and must be handled in the public interest.

4. RESPONSIBILITY OF THE GRANT RECIPIENT

Any individual, institution or organisation accepting a grant from the fund accepts full responsibility and legal liability for any act or acts related to, or arising from, any project supported by the fund and the fund shall not be responsible or liable for such act or acts in any way.

5. FINAL REPORT

The grant recipient shall provide a final report at completion, and this report should include a list of publications arising from the research.

6. PUBLICATION OF RESULTS

Recipients of grants from the fund are expected to make their results available through relevant and appropriate scientific publications and meetings. Recipients shall not make public the results of their research through any other channels without the prior written approval of the fund. Grant recipients may indicate their status as a grant recipient in scientific publications and programs of scientific meetings, but not in any other public connection.

The fund should be acknowledged in any publications arising from the research where part or full funding has been provided. A reprint or digital link of any journal publication or a copy of any monograph or print publication on the work shall be provided to HFA.

7. APPLICATION FORM

Applications must be made on the form which can be download form from the HFA website www.haemophiia.org.au/research

8. CLOSING DATE

Applications must be made on the form provided and submitted by email with any attachments to hfaust@haemophilia.org.au by 30 August 2022.

Receipt of application will be acknowledged by email.

No late applications will not be accepted.