

National Hemophilia Foundation
Research Grants Program
Policies and Procedures

September 2003

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NHF Research Priorities

The National Hemophilia Foundation funds a broad range of research to lead to improvements in the lives of people with bleeding disorders. Its Judith Graham Pool Postdoctoral Research Fellowship program, founded in 1972, sponsors an array of clinical and basic research in the hemophilias or von Willebrand disease. The Nursing, Social Work, and Physical Therapy Excellence Fellowships provide support to practitioners to conduct nursing, psychosocial, and physical therapy research in the field of bleeding disorders.

NHF's Career Development Award, created under the *It's Time for a Cure* campaign, is designed to fund research into cures for bleeding disorders. This grant supports investigators at the assistant professor level who have demonstrated a commitment to bleeding disorders research.

It's Time for a Cure

In 1998, the National Hemophilia Foundation (NHF) launched a five-year capital campaign entitled *It's Time for a Cure* to raise \$5 million for research specifically into cures for bleeding disorders. The campaign was renewed in 2002 with a drive to raise \$10 million over five years. The money raised by this campaign will bolster NHF's research program by creating new levels of multiyear study and support for scientists working in the field of inherited bleeding disorders. Grants awarded under this program will complement NHF's existing research fellowships.

Types of Application

Career Development Award - Awards \$70,000 per year for up to three years. The grant will fund researchers at the assistant professor level who have demonstrated a commitment to bleeding disorder research.

Judith Graham Pool Postdoctoral Fellowship - Awards \$42,000 per year for up to two years. The grant supports researchers who have completed doctoral training and enter from a doctoral, postdoctoral, internship, or residency training program.

Nursing Excellence Fellowship - Awards up to \$20,000 for one year or 18 months. The grant provides support for a registered nurse currently employed or interested in hemophilia care to conduct nursing research or clinical projects.

Social Work Excellence Fellowship - Awards up to \$10,000 for one year. The fellowship funds a social worker interested in bleeding disorders care for conducting research or a clinical project of relevance and benefit to the bleeding disorders community.

Physical Therapy Excellence Fellowship - Awards up to \$5,000 for one year. The fellowship funds a physical therapist interested in bleeding disorders care for conducting research or a clinical project of relevance to the bleeding disorders community.

Deadlines

Type of Application	Letter of Intent	Application Deadline	Review	MASAC/ BOARD Approval	Official Notice	Start Date
Career Development Award	November 1	February 1	April/May	May/June	June	July 1
JGP Postdoctoral Fellowship	N/A	Dec. 1	March/April	May	May/June	July 1
Nursing Excellence Fellowship	February 1	April 1	April/May	May	May/June	July 1
Social Work Excellence Fellowship	N/A	April 1	April/May	May	May/June	July 1
PT Excellence Fellowship	N/A	April 1	April/May	May	May/June	July 1

Administration

- The Research Department at the National Hemophilia Foundation, with counsel from scientific and lay leaders, is responsible for the administration of the grant programs.
- Grantees are not employees of NHF but of their grantee institution and are subject to the policies and regulations of the grantee institution.
- Only noncommercial institutions and investigators associated with a noncommercial institution are eligible for NHF funding.
- NHF is a nonprofit organization and all grants are offered based on fundraising efforts; therefore, all grants and fellowships are contingent on funds available.

Peer Review Process

All grant and fellowship applications are subjected to a rigorous peer review process. Applications that are incomplete or that do not follow all instructions will be returned. Applicants are critiqued on scientific merit and relevance to NHF research priorities. Applications are reviewed and scored in the following categories:

Significance: Does this study address an important problem facing the bleeding disorders community? If the aims of the application are achieved, how will scientific knowledge of bleeding disorders be advanced? What will be the effect of these studies on the concepts or methods that drive this field?

Approach: Are the conceptual framework, design, methods, and analyses adequately developed, well integrated, and appropriate to the aims of the project? Does the applicant acknowledge potential problem areas and consider alternative tactics?

Innovation: Does the project employ novel concepts, approaches or methods? Are the aims original and innovative? Does the project challenge existing paradigms or develop new methodologies or technologies?

Investigator: Is the investigator appropriately trained and well suited to carry out this work? Is the work proposed appropriate to the experience of the PI or fellow and other researchers?

Environment: Does the scientific environment in which the work will be done contribute to the probability of success? Do the proposed experiments take advantage of the scientific environment or employ useful collaborative arrangements? Is there evidence of institutional support?

Applications will be peer reviewed by a panel selected by the Research Working Group, a volunteer body composed of scientific and lay members. Final funding approval is granted by the NHF Medical and Scientific Advisory Council (MASAC) and the NHF Board of Directors.

Change in Status

The grantee is responsible for contacting the Research Department at NHF if there are any changes in status in the grantee institution, sponsor or mentor (JGP fellowship only), budget, or in the status of pending grants. The grantee and his/her sponsor or mentor are expected to remain at their institution for the duration of the project. In the event that the grantee, sponsor, or mentor does leave the institution, s/he should notify National Hemophilia Foundation's Director of Research immediately. The transfer of the project to another institution or investigator is in NHF's sole discretion. Any changes in budget after a grant or fellowship is awarded must be requested in writing and the justification must be explained in detail. NHF retains sole discretion to reject or accept budget changes.

Additional Funding

Applicants must submit information on all current and pending funding sources to the NHF Research Department. It is permissible for an applicant's project to receive additional funding from another source. In the event of a change in the status of a pending application, all grantees are required to notify the NHF Research Department.

Termination of Support

NHF reserves the right to terminate support of a funded project at any time for any reason in its sole discretion.

Publications

Grantees are required to place an acknowledgment of NHF grant support on any publication. Publications resulting from research funded by NHF must accompany progress reports. The National Hemophilia Foundation reserves the right to publish, reproduce, and distribute nonconfidential material generated from all projects. All work including, but not limited to, videos, written reports, and other materials deriving from a project shall remain the property of the National Hemophilia Foundation.

Availability of Research Results and Resources

Restricted availability of research results or resources upon which further studies are dependent can impede the advancement of research and the delivery of medical care. Therefore, results and resources developed while funded by an NHF grant must be made available for research purposes to qualified individuals within the scientific bleeding disorders community. Categories of these resources include but are not limited to synthetic compounds, organisms, cell lines, viruses, cell products, cloned DNA, DNA sequences, mapping information, crystallographic coordinates, and spectroscopic data.

Human Subjects

The applicant's institution has the primary responsibility for protecting the rights and welfare of human subjects in any research activity supported by the National Hemophilia Foundation. Applicants requesting funding for research involving human subjects must submit written approval of the research project from the institution's Institutional Review Board. No funds will be awarded until these materials are received, reviewed, and approved by NHF. It is the responsibility of the awardee and the institution to notify NHF of all changes to the research protocol involving human subjects.

Use of Animals in Research

National Institutes of Health policy defines animals as “any live, vertebrate animal used or intended for use in research, research training, experimentation, or biological testing or for related purposes.” NHF adheres to the following principles regarding the use of animals in research:

1. Animals shall be used in research only when no other means of obtaining scientifically sound, valid, and useful results are available.
2. The minimum number of appropriate animals required to obtain and validate results shall be used.
3. The acquisition, care, and use of animals must be in accordance with all applicable federal, state, and local laws and regulations.
4. Certifications must be received from research facilities prior to being approved for a research grant that the facility(ies), its researchers, and employees adhere to the Animal Welfare Act, National Research Council *Guide for the Care and Use of Laboratory Animals*, the standards for laboratories established by the Association for the Assessment and Accreditation of Laboratory Animal Care International, and any appropriate U.S. Department of Agriculture or National Institutes of Health regulations and standards. No funds will be awarded until these materials are received, reviewed, and approved by NHF.
5. In cases requiring the death of an animal, only the most appropriate and humane form of euthanasia shall be used consistent with the purpose of the research.

It is the responsibility of the awardee and the institution to notify NHF of all changes to the research protocol involving animals.

Inventions and Patents

All NHF grants are subject to NHF's policy on inventions and patents. By accepting an award for a research project, the principal investigator or other personnel contributing to and working on the project, as well as the institution(s) with which they are affiliated, agree to be bound by the terms and conditions of NHF's policy on inventions and patents.

NHF understands that patents and licensing agreements may be sought on inventions resulting from research by the grant recipient supported in whole or in part by funds furnished by NHF; that such inventions should be administered so that they are introduced into public use as soon as practicable; and that such result will be achieved through granting permission to patent and license such inventions. Accordingly, it adopts the following policy:

1. An invention (hereinafter "NHF invention") resulting from the support in whole or in part to the grant recipient of funds awarded by NHF shall be reported promptly in writing to NHF's Research Department.
2. If the university or other research institution or an individual investigator(s) associated therewith ("Institution" or "Investigator") which is the recipient of financial support for the work leading to the NHF invention has an established patent and licensing policy and procedure for procuring and administering inventions which are known to and accepted by NHF, or has an agreement with another organization, including agencies or departments of the U.S. government relating to the NHF invention due to joint support, NHF will defer to that policy or agreement on the following terms:
 - a. With respect to any such invention, the Institution or Investigator shall have the right to file a patent application, and if the Institution or Investigator decides not to file a patent application, NHF shall be notified thereof within a reasonable time and NHF shall have the right to file a patent application. On any Institution- or Investigator-filed or NHF-filed patent application and on any patent obtained thereof or thereon, NHF shall have a nonexclusive, nontransferable, irrevocable, paid-up license to practice or have practiced for and on its behalf any such invention and to grant sublicenses thereunder. The patent application(s) and patent(s) obtained thereon shall embrace the United States and all countries outside of the United States. The inventions herein above contemplated shall include those made by employees or agents of the Institution or Investigator and third parties under the control of the Institution or Investigator.
 - b. The Institution or Investigator will notify NHF in writing of any decision not to continue the prosecution of a patent application, pay maintenance fees, or defend a reexamination or opposition proceeding on a patent, in any country, not less than thirty days before the expiration of response period required by the relevant patent office. The grantee institution will convey to NHF, upon written request, title to any such patent application or patent.
 - c. The Institution or Investigator will make the invention available for commercial licensing upon reasonable terms and conditions.
 - d. From the monies, if any, received from licensing the invention, NHF and the Institution or Investigator and all other parties shall share on terms mutually agreed upon by the Institution or Investigator and NHF, such terms to be determined prior to any licensing or commercial exploitation of the invention with

NHF's share being at least equal to the percent of total funding that NHF has provided to support the specific research project through grants and awards.

- e. In the event that it obtains a patent, license arrangement or other commercial exploitation of an invention, the Institution or Investigator shall make periodic reports to NHF with respect to its utilization of the invention and account for any income received by it by reason of exploitation of the invention.
 - f. NHF agrees that if it, or its licensee, has not taken effective steps within two years (or such lengthier period agreed to by NHF and the Institution or Investigator) after a United States patent issues on an NHF invention left for administration to the Institution or Investigator to bring the NHF invention to the point of practical application, and the Institution or Investigator cannot establish to NHF's satisfaction that it should retain all rights, title, and interest to an NHF invention for a further time period, the Institution or Investigator upon NHF's request shall: (1) assign said patent, and (2) cancel any outstanding exclusive licenses under said patent, and NHF shall have the right to require the Institution or Investigator to grant licenses under said patent to an applicant on a nonexclusive, royalty-free basis or on such other terms as NHF may request.
 - g. If NHF and the Institution or Investigator are unable to settle upon participation in licensing terms or other items in 2a-2f by mutual agreement, such participation shall be determined pursuant to arbitration by a majority of three arbitrators. NHF and the Institution or Investigator shall each designate an arbitrator, and the two so selected shall select a third. Any such arbitration proceeding shall be conducted in accordance with the rules of the American Arbitration Association.
3. If the Institution or Investigator has no patent or licensing policy and procedure for administering inventions, NHF shall have the right to determine the disposition of the invention rights in any such case.

Scientific Misconduct and Fraud

The grantee institution is responsible for having and instituting a written policy or guidelines on conflict of interest and scientific misconduct and fraud. This policy must be supplied to NHF. It is the responsibility of the institution and the awardee to inform NHF of any institutional investigation involving the conduct of an investigator funded by NHF. It is also the responsibility of the institution and grantee to keep NHF informed of the progress and outcome of the investigation. Findings of fraud or misconduct are sufficient grounds to terminate support of the funded project.

Assurance of Compliance

NHF complies with all relevant state and federal equal opportunity and discrimination laws and regulations and requires all institutions awarded funds from NHF also to comply with relevant state and federal equal opportunity and discrimination laws and regulations.

Inquiries

For applications, policies and procedures, and programmatic information, please contact:

Rita C. Barsky, Ph.D.
Assistant Director of Research
National Hemophilia Foundation
116 West 32nd Street, 11th Floor
New York, NY 10001
800-424-2634 ext. 3730 or 212-328-3730
FAX 212-328-3788
E-mail rbarsky@hemophilia.org.

Direct inquiries regarding fiscal matters to:

Zena Santa Catalina
Director of Finance and Administration
National Hemophilia Foundation
116 West 32nd Street, 11th Floor
New York, NY 10001
800-424-2634 ext. 3721 or 212-328-3741
FAX 212-328-3788
E-mail: zsantacatalina@hemophilia.org

Career Development Award

Eligibility

Candidates must hold an MD, PhD, or equivalent degree and be an assistant professor (or equivalent) with up to six years of experience since completion of training. Individuals with more than six years of previous postdoctoral experience are discouraged from applying. Applicants may be affiliated with or be faculty members of domestic organizations such as universities, colleges, hospitals, and laboratories. U.S. citizenship is not required. The applicant is expected to spend at least 90% of the working time on research. Letters of support by appropriate institutional officials (department chair or other) indicating institutional commitment of sufficient time to permit the candidate to focus his or her efforts on research should be submitted with the application. The candidate must spend at least 25% of his/her time working on the research award in order to request salary support. Candidates may request up to 90% of annual salary support in the award.

Funding

NHF awards up to three grants of \$70,000 per year for up to three years.

Deadlines

All applicants must submit a letter of intent by November 1. This should be a brief letter identifying the applying researcher and organization and the intended area of research. Letters of intent should include an NIH-style biosketch for both candidate and preceptor. Letters of intent will be evaluated by members of the Research Working Group who will make final recommendations with respect to application submissions.

Applications are to be submitted on the NHF Career Development Award application form. Applications must be submitted by the deadline of February 1. The application must be delivered by the deadline. If February 1 falls on a Saturday or Sunday, the application is due the first Monday of the month. Funding will begin July 1.

Application Forms

Applications are not sent to institutions for general distribution. Applicants can download the application from the NHF website or request application forms from the NHF Research Department.

The application must be submitted in 15 copies (original and 14 copies), in typed single-space format and spaced within the margin limitations indicated on the form. Send original and copies of completed application with all supporting documents and letters of recommendation to:

**Research Department
National Hemophilia Foundation
116 W. 32nd Street, 11th Floor
New York, NY 10001**

Use standard size black type that can be photocopied; do not use photoreduction. Do

not use type size smaller than 10 points. Do not staple sets. Please use a rubber band, paper clip, or binder to secure the applications. The application cannot be considered for review unless signed by the applicant and the financial officer.

Terms

The Career Development Award can be awarded for one, two, or three years. Continuation of the second and third year requires the submission of a continuation application and administrative approval.

Application Instructions

Letters of recommendation must be sent with the application from:

- a. Current department chairperson or chairpersons
- b. Doctoral advisor, former professor, or scientist familiar with work or potential. (If possible, this should be from another institution.)

Description of proposed research project. (Continue as page 8 of the application and label each section as below. The limit is 10 additional pages for sections A-F. Applications exceeding the 10-page limitation will be returned and not reviewed.) The research description should include sufficient information needed for evaluation of the project, independent of any other document. Be specific and informative, and avoid redundancies.

- A. Specific aims for the project. Include a statement of your hypotheses.
- B. Background and significance. Describe the background leading to the present application, evaluate existing knowledge, and identify gaps the project is intended to fill.
- C. Preliminary studies by applicant, if any. (If none, state "none".) Relevant manuscripts and published papers by the applicant may be submitted as supplemental materials. No more than two relevant publications can be submitted with the application. All publications must be photocopied, do not use staples.
- D. Experimental design and methods. Describe the research design and the procedures to be used to accomplish the specific aims of the project. Indicate how the data will be collected, analyzed, and interpreted. Discuss the potential difficulties and limitations of the proposed procedures and alternative approaches to achieve the aims.
- E. State if work requires human research, animal care, biosafety, or radiation safety, and provide date of committee approval. If work requires IRB/IACUC approval, fill out the assurance/certification page.
- F. Include at least one-half page that describes where future studies would be directed if all of the specific aims listed in section A are accomplished.
- G. Cited references.

- H. Letters of recommendation and any letters from suppliers of major scientific materials (monoclonal antibodies, DNA clones, etc.) from other institutions. (Include as appendix)

Authorized Expenses

The following expenses are, when the National Hemophilia Foundation deems them justified by the research, permitted under the institutional overhead. All expenses must be justified, use additional pages if necessary.

1. Salary and fringe benefits for the grantee, but may not exceed the percent effort on the project multiplied by the investigator's salary.
2. Equipment and supply expenses necessary to fulfill the project's specific aims (if purchased solely with NHF funds, equipment should reside with the project for which it was funded).
 - a. Purchase of equipment is not allowed in the second and third year of the grant.
3. Travel expenses:
 - a. Directly related to the implementation of the research;
 - b. Expressly and solely for the purpose of reporting the results of NHF-supported research at suitable scientific or medical meetings;
 - c. Limited to \$1,000 maximum per year.
4. Costs associated with publication of the research.
5. Costs associated with making the products of the research (i.e., cell lines, DNA, protein, and other biological substances) available to others for research.
6. Certain patient care costs. Funds requested for hospitalization and/or professional medical services for study subjects may be granted if justification is presented in the application to show that such charges are needed for the research proposed and that the usual sources available for these costs are not adequate. All third-party payments received by the grantee institution for such services are to be used to offset the funds awarded in the grant for this purpose.
7. Indirect costs not to exceed 8% of direct costs.

Unauthorized Expenses

1. The following expenses are not permitted under NHF's research program:
2. Salary or fringe benefits for anyone other than the grantee.
3. Salaries, travel, and/or housing related to sabbatical leaves.
4. Purchase or rental of office equipment (i.e., typewriters, word processors, furniture, filing cabinets, and copy machines).

5. Consultant costs.
6. Expenses normally covered by the indirect cost of the grantee's institution.
7. Fees for tuition.
8. Membership dues, subscriptions, books, or journals.

Notification

After final approval by the NHF Board of Directors, all applicants will be mailed notification of their status. All grantees are required to send a letter of acceptance, enter into an acceptable agreement outlining obligations and understandings, and submit semi-annual progress reports and financial reports from their institution stating the grant has been received and expended.

Unobligated Funds

Because budgets in applications for grants are estimates of the funds required to perform the research indicated, unexpended funds may remain at the end of each year and at the termination of the grant. Any unexpended funds remaining at the end of each year may be carried over to the next year. However, unexpended funds remaining after the termination of the grant must be returned to NHF.

Financial Reports

Grantees must submit financial reports from their institution stating the grant has been received and expended. Annual financial reports are due by August 1. Final financial reports are due 60 days from the termination of the grant.

Progress Reports and Continuation of Grants

All grantees are required to submit semi-annual progress reports due January 1 and July 1. Grantees intending to continue funding after the first year must substitute the continuation application for the January 1 semi-annual progress report. Payment and subsequent years is dependent on funding and receipt, review, and approval by NHF's Research Working Group of annual financial reports, continuation application, and progress reports.

Final Research Report

A final report consisting of a summary in lay language of the research accomplished, a list of the resulting publications, and a copy of each publication must be provided within sixty days after termination of the grant. This report is in addition to any interim progress report that may have been included in an application to NHF for further research support.

Publications and Presentations

NHF must be acknowledged in any publications, including abstracts, which result from the funded research. In addition, NHF may ask the awardee to present the research at the NHF annual meeting and summarize it for an NHF publication.

JUDITH GRAHAM POOL POSTDOCTORAL RESEARCH FELLOWSHIPS

Eligibility

Applicants must have completed doctoral training and must enter the JGP fellowship program from a doctoral, postdoctoral, internship, or residency training program. Established investigators or faculty members are not eligible. Applicants must be affiliated with domestic organizations such as universities, colleges, hospitals, and laboratories. U.S. citizenship is not required.

Permissible research topics include clinical or basic research on the biochemical, genetic, hematologic, orthopedic, psychiatric, or dental aspects of the hemophilias or von Willebrand disease. Other topics include rehabilitation, therapeutic modalities, psychosocial issues, women's health issues, liver disease, or AIDS/HIV as they pertain to the hemophilias or von Willebrand disease.

It is expected that the fellow will spend at least 90% of the time on the research project for which funding is requested. The remaining 10% may be devoted to teaching or clinical work that is relevant to the research.

Funding

NHF awards up to four fellowships per year of \$42,000 each.

Deadlines

The deadline for submitting copies of the application form and all other supporting documents, including required letters of reference, is December 1. The application must be delivered by the deadline. If December 1 falls on a Saturday or Sunday, the application is due the first Monday of the month.

Application Forms

Applications are not sent to institutions for general distribution. Applicants can download the application from the NHF website or request application forms from the NHF Research Department.

The application must be submitted in 15 copies (original and 14 copies), in typed single-space format and spaced within the margin limitations indicated on the form. Send original and copies of **completed application with all letters** to:

**Research Department
National Hemophilia Foundation
116 W. 32nd Street, 11th Floor
New York, NY 10001**

Use standard size black type that can be photocopied; do not use photoreduction. Do not use type size smaller than 10 points. Do not staple sets. Please use a rubber band, paper clip, or binder to secure the applications. The application cannot be considered for review unless signed by the applicant, the sponsor, and the financial officer.

Terms: The JGP fellowship can be awarded for up to two years. Continuation of the JGP awards for a second year requires submission of a continuation application and administrative approval.

Application Instructions

Letters of Reference must be sent with the application from:

- a. Sponsor
- b. Department Chairman
- c. Doctoral advisor, former professor, or scientist familiar with work or potential. (If possible, this should be from another institution.)

Description of proposed research project. Continue as page 9 of this application and label each section as below. The limit is 8 additional pages for sections A-G. Figures or tables must be included in above page limitations. Applications exceeding the 8-page limitation will be returned and not reviewed.

- A. Specific aims for project. Include a statement of your hypotheses.
- B. Background and significance. Describe the background leading to the present application, evaluate existing knowledge, and identify gaps the project is intended to fill.
- C. Preliminary studies by applicant, if any. (If none, state "none".) Relevant manuscripts and published papers by the applicant may be submitted as supplemental materials. No more than two relevant publications can be submitted with the application. All publications must be photocopied, do not use staples.
- D. Experimental design and methods. Describe the research design and the procedures to be used to accomplish the specific aims of the project. Indicate how the data will be collected, analyzed, and interpreted. Discuss the potential difficulties and limitations of the proposed procedures and alternative approaches to achieve the aims. (If statistics are used, how many individuals will be required for significance and how will they be analyzed?)
- E. State if work requires human research, animal care, biosafety, or radiation safety and date of committee approval. If work requires IRB/IACUC approval, fill out the assurance/certification page.
- F. Include at least one-half page that deals with anticipated problems and how they will be overcome.
- G. Include at least one-half page that describes where future studies would be directed if all of the specific aims listed in section A are accomplished.

- H. Cited references.
- I. Letters of recommendation and any letters from suppliers of major scientific materials (monoclonal antibodies, DNA clones, etc.) from other institutions. (Include as appendix)

Authorized Expenses

The following expenses are, when the National Hemophilia Foundation deems them justified by the research, permitted under the institutional overhead:

1. Salary and fringe benefits for the fellow.
2. Equipment and supply expenses necessary to fulfill the project's specific aims (if purchased solely with NHF funds, equipment should reside with the project for which it was funded).
 - a. Equipment expenses may not exceed \$3,000 in any given year.
3. Travel expenses:
 - a. Directly related to the implementation of the research;
 - b. Expressly and solely for the purpose of reporting the results of NHF-supported research at suitable scientific or medical meetings;
 - c. Limited to \$1,000 maximum per year.
4. Costs associated with publication of the research.
5. Costs associated with making the products of the research (i.e., cell lines, DNA, protein, and other biological substances) available to others for research.

Unauthorized Expenses

The following expenses are not permitted under NHF's research program:

1. Salary or fringe benefits for anyone other than the grantee.
2. Salaries, travel, and/or housing related to sabbatical leaves.
3. Purchase or rental of office equipment (i.e., typewriters, word processors, furniture, filing cabinets, and copy machines).
4. Indirect costs.
5. Consultant costs.
6. Expenses normally covered by the indirect cost of the grantee's institution.
7. Fees for tuition.
8. Membership dues, subscriptions, books, or journals.

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After final approval by the NHF Board of Directors, all applicants will be mailed notification of their status. All fellows are required to send a letter of acceptance, enter into an acceptable agreement outlining obligations and understandings, and submit semi-annual progress reports and financial reports from their institution stating the grant has been received and expended.

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Because budgets in applications for grants are estimates of the funds required to perform the research indicated, unexpended funds may remain at the end of each year and at the termination of the grant. Any unexpended funds remaining at the end of each year may be carried over to the next year. However, unexpended funds remaining after the termination of the grant must be returned to NHF.

Financial Reports

Grantees must submit financial reports from their institution stating the grant has been received and expended. Annual financial reports are due by August 1. Final financial reports are due 60 days from the termination of the grant.

Progress Reports and Continuation of Grants

All grantees are required to submit semi-annual progress reports due January 1 and July 1. Grantees intending to continue funding after the first year must substitute the continuation application for the January 1 semi-annual progress report. Payment and subsequent years is dependent on funding and receipt, review, and approval by NHF's Research Working Group of annual financial reports, continuation application, and progress reports.

Final Research Report

A final report consisting of a summary in lay language of the research accomplished, a list of the resulting publications, and a copy of each publication must be provided within sixty days after termination of the grant. This report is in addition to any interim progress report that may have been included in an application to NHF for further research support.

Publications and Presentations

NHF must be acknowledged in any publications, including abstracts, which result from the funded research. In addition, NHF may ask the awardee to present the research at the NHF annual meeting and summarize it for an NHF publication.

NURSING EXCELLENCE FELLOWSHIP

Description

The National Hemophilia Foundation Nursing Excellence Fellowship awards financial support to a registered nurse to conduct a research, clinical, or educational project. These projects, which are awarded through a competitive review process, are initiated to improve the delivery of care and expand the knowledge of nursing science surrounding bleeding disorders. Projects awarded the fellowship are consistent with the purpose and goals of the Nursing Working Group of the National Hemophilia Foundation:

- Enhance and promote standards of hemophilia, bleeding disorders, and thrombophilia nursing practice.
- Support and foster the professional development of hemophilia, bleeding disorders, and thrombophilia nursing through education, collaboration, and nursing research.
- Facilitate health promotion and education within the bleeding disorders community.

The Award

Funding varies from year to year based on interest received from the Soozie Courter Memorial Fund. Awards will be at least \$10,000 per year. Applicants should consult with the NHF Research Department to determine the precise amount of funding available. Applicants may request any amount between \$5,000 and the maximum amount available depending upon the scope of the research, clinical, or educational project. Awards are made for either 12 or 18 months. The time frame selected at the time of application must be followed.

Eligibility

Eligible applicants include registered nurses currently employed or highly interested in hemophilia nursing care. Endorsement by a hemophilia treatment center is recommended. Only registered nurses enrolled in a graduate nursing program from an accredited nursing school or practicing hemophilia nursing care may apply.

Projects

Projects eligible for the Nursing Excellence Fellowship can be designed as a research study, a clinical project, or an educational project. This year the National Hemophilia Foundation has expanded the fellowship to include educational projects as described below. Although all types of projects will be considered in the application process, research projects will be given priority.

1. Research Project:

A research project is one that asks a research question that is answered through rigorous systematic methods. These projects may include but are not limited to research that investigates measurable outcomes in bleeding disorders care, epidemiology of bleeding disorders, and aspects of hemophilia nursing care. As

mentioned previously, research projects will be given priority in the selection process.

2. **Clinical Project:**
Clinical projects seek to improve hemophilia nursing care through the development of tools that may augment the delivery of care. Examples of this may include but are not limited to development of clinical pathways and creating measurement tools (e.g., quality of life).
3. **Educational Project:**
Education is the cornerstone of hemophilia nursing care. Projects that provide relevant educational programs, develop educational materials, or develop innovative educational tools for patients and the community are examples of these types of projects.

Collaboration

Collaboration with multidisciplinary care providers and between two or more hemophilia treatment centers is encouraged. Collaboration efforts may include social work, physical therapy and genetics. It may be possible for a hemophilia center team to apply jointly for two or more of the nursing, social work, and physical therapy excellence fellowships as a cooperative project or research endeavor. Additionally, regional collaborations are encouraged and will be considered.

Deadlines:

A letter of intent must be received by NHF by February 1. This should be a brief letter that includes the rationale, design, methods, goals and objectives of the project. Eligible applicants will be sent an invitation to apply for the fellowship.

The deadline for submitting copies of the application form and all supporting documents, including the letters of reference, is April 1. The application must be delivered by the deadline. The winner(s) of the Nursing Fellowship will be notified by June 15.

Publications and Presentations:

NHF requests that it is acknowledged in abstracts and publications which result from the funded project. In addition, NHF may ask the awardee to present the results at the NHF annual meeting and summarize it for an NHF publication. This is so that the national hemophilia community can be informed and benefit from the Nursing Excellence Fellowship award project.

Application Forms

Applications are not sent to institutions for general distribution. Applicants can download the application from the NHF web site or request application forms from the NHF Research Department. Complete application instructions can be found on the web site.

Notification

After final approval by the NHF Board of Directors, all applicants will be mailed notification of their status. All grantees are required to send a letter of acceptance, enter into an acceptable agreement outlining obligations and understandings, and

submit quarterly progress reports and financial reports from their institution stating the grant has been received and expended.

For applications, policies and procedures, and programmatic information, please contact:

Morgan Johnson, Coordinator of Research Programs
National Hemophilia Foundation
116 West 32nd Street, 11th Floor
New York, NY 10001
800-424-2634 ext. 3745 or 212-328-3745
FAX 212-328-3788
E-mail: mjohnson@hemophilia.org.

or consult the National Hemophilia Foundation web site at www.hemophilia.org.

SOCIAL WORK EXCELLENCE FELLOWSHIP

Eligibility

To be eligible for the fellowship the applicant must: be an MSW from an accredited school of social work or be a student in a DSW program or have a master's degree in a social work related field, be licensed by the state to practice as a master's level clinical social worker and work in a bleeding disorders program. Professional experience in a hemophilia treatment center is desirable but not required. The proposed project, however, must have relevance to current practice in bleeding disorders care and may incorporate casework, group work, organizational and public health, education, and research perspectives.

It is expected that the project will: (1) promote the integration of psychosocial care with biomedical components of comprehensive care; (2) promote the delivery of quality services to patients and families; (3) contribute to the literature on the psychosocial aspects of bleeding disorders; (4) demonstrate social work outcomes of the research or clinical project.

Collaboration with multidisciplinary care providers and/or between two or more hemophilia centers is accepted and encouraged. Collaboration efforts may include, for example, nursing, physical therapy, and genetics. It thus may be possible for a hemophilia center team to apply jointly for two or more of the nursing, social work, and physical therapy excellence fellowships as a cooperative project or research endeavor. Additionally, regional applications will be considered.

Areas of research interest might include some of the following topics: impact of social work practice on coping with chronic illness and/or disability; impact of case management on patient care; improved clinical practice; research skills and goals for psychosocial providers; mental health issues of those affected with bleeding disorders

or bleeding disorders/HIV; development and use of media projects and/or learning tools for professional or patient evaluation. A focus on cultural diversity is welcomed.

Funding

NHF awards one new research fellowship per year of \$10,000.

Deadlines

A letter of intent should be submitted to NHF by February 1. This should be a brief letter identifying the prospective researcher and organization and the intended area of research. The purpose of this letter is to allow the prospective researcher to receive guidance and technical support from the Social Work Working Group and NHF staff without having to first develop a fully formed proposal. Inquiries to a SWWG representative and/or NHF staff member are highly encouraged.

The deadline for submitting copies of the application form and all other supporting documents, including required letters of reference, is April 1. The application must be delivered by the deadline. If April 1 falls on a Saturday or Sunday the application is due the first Monday of the month.

Application Forms

Applications are not sent to institutions for general distribution. Applicants can download the application from the NHF website or request application forms from the NHF Research Department.

The application must be submitted in 5 copies (original and 4 copies), in typed single-space format and spaced within the margin limitations indicated on the form. Send original and copies of **completed application with all letters** to:

**Research Department
National Hemophilia Foundation
116 W. 32nd Street, 11th Floor
New York, NY 10001**

Use standard size black type that can be photocopied; do not use photoreduction. Do not use type size smaller than 10 points. Do not staple sets. Please use a rubber band, paper clip, or binder to secure the applications. The application cannot be considered for review unless signed by the applicant, the mentor, and the financial officer.

Terms

Each year one new research fellowship of \$10,000 will be awarded. Awards are made for one calendar year.

Application Instructions

Letters of reference must be sent with the application from three persons, two with expertise in bleeding disorders. Suggested referents include, but are not limited to:

- A hemophilia treatment center director

- A social work faculty member familiar with the applicant's academic career
- A social worker whose practice includes work within the bleeding disorders community
- A bleeding disorders community leader (e.g., chapter president)

Description of proposed research project. (Continue as page 9 of this application and label each section as below. The limit is 8 additional pages for sections A-F. Figures or tables must be included in above page limitations. **Applications exceeding this limitation will be returned and not reviewed.**

- A. Objectives (include a statement of your hypotheses).
- B. Theoretical background and significance.
- C. Preliminary studies by applicant, if any. (If none, state "None".) *If a manuscript of the applicant is in press, publication date and the journal to which it was submitted should be stated in this section.*
- D. Design methods (including sample descriptions, interventions [if any] and measures).
- E. If work requires IRB/IACUC approval, state how confidentiality will be maintained. Please fill out the assurance/certification page accompanied by the IRB/IACUC approval letter.
- F. Please submit a timeline for your project.
- G. Describe how results will be shared with the bleeding disorders community.

Authorized Expenses

The following expenses are, when the National Hemophilia Foundation deems them justified by the research, permitted under the institutional overhead:

1. Salary and fringe benefits for the grantee.
2. Equipment and supply expenses necessary to fulfill the project's specific aims (if purchased solely with NHF funds, equipment should reside with the project for which it was funded).
 - a. Equipment expenses may not exceed \$3,000 in any given year.
3. Travel expenses:
 - a. Directly related to the implementation of the research;
 - b. Expressly and solely for the purpose of reporting the results of NHF-supported research at suitable scientific or medical meetings;
 - c. Limited to \$1,000 maximum per year.

4. Costs associated with publication of the research.

Unauthorized Expenses

The following expenses are not permitted under NHF's research program:

1. Salary or fringe benefits for anyone other than the grantee.
2. Salaries, travel, and/or housing related to sabbatical leaves.
3. Purchase or rental of office equipment (i.e., typewriters, word processors, furniture, filing cabinets, and copy machines).
4. Indirect costs.
5. Expenses normally covered by the indirect cost of the grantee's institution.
6. Fees for tuition.
7. Membership dues, subscriptions, books, or journals.

Notification

After final approval by the NHF Board of Directors, all applicants will be mailed notification of their status. All grantees are required to send a letter of acceptance, enter into an acceptable agreement outlining obligations and understandings, and submit quarterly progress reports and a final financial report from their institution stating the grant has been received and expended.

Unobligated Funds

Because budgets in applications for grants are estimates of the funds required to perform the research indicated, unexpended funds may remain at the end of each year and at the termination of the grant. Unexpended funds remaining after the termination of the grant must be returned to NHF.

Financial Reports

Grantees must submit a final financial report from their institution stating the grant has been received and expended. The final financial report is due 60 days from the termination of the grant.

Progress Reports

All grantees are required to submit quarterly progress reports due October 1, January 1, and April 1.

Final Research Report

A final report of the research accomplished, a list of the resulting publications, and a copy of each publication must be provided within sixty days after termination of the grant. This report is in addition to any interim progress report that may have been included in an application to NHF for further research support.

Publications and Presentations

NHF must be acknowledged in any publications, including abstracts, which result from the funded research. In addition, NHF may ask the awardee to present the research at the NHF annual meeting and summarize it for an NHF publication.

PHYSICAL THERAPY EXCELLENCE FELLOWSHIP

Eligibility

To be eligible for the fellowship the applicant must be a physical therapist from an accredited physical therapy school currently working with patients with bleeding disorders. Endorsement by a federally funded hemophilia treatment center is recommended.

The objectives of the Physical Therapy Fellowship are to improve the delivery of physical therapy care and expand the knowledge base specific to hemophilia. It is expected that the fellowship will provide support for a physical therapist currently employed or interested in hemophilia care to conduct physical therapy research, or clinical projects related to the care of the patient with hemophilia.

Current topics of interest may include but are not limited to the following: development of clinical pathways, physical therapy protocols, physical therapy utilization, measurable outcome studies, rehabilitation programs, use of modalities and other intervention commonly used by physical therapists in the treatment of the patient with hemophilia. Awards are made for one calendar year.

Funding

NHF awards one new research fellowship per year of \$5,000.

Deadlines

The deadline for submitting copies of the application form and all other supporting documents, including required letters of reference, is April 1. The application must be delivered by the deadline. If April 1 falls on a Saturday or Sunday the application is due the first Monday of the month.

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Terms

Awards are made for one calendar year.

Application Instructions

Letters of reference must be sent with the application from three persons, two with expertise in bleeding disorders. Suggested referents include, but are not limited to:

- A hemophilia treatment center director
- A physical therapy faculty member familiar with the applicant's academic career
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