



2019 Grant Guidance



Be sure to check out what's new

Have a Question? Read the Guidance.

Still have a question?

Feel free to call or email the
Hemophilia Alliance Foundation
Board Chair, Joyce Strazzabosco,
315-226-2196 (cell)

Call between 10:00 a.m. and 6:00 p.m. Eastern Time
or email

joyce@hemophiliaalliancefoundation.org

2019 Hemophilia Alliance Foundation Grant Guidance

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I. History

The Hemophilia Alliance, a nonprofit corporation, was incorporated in 2005 as a member organization for hemophilia treatment centers. Together they are able to purchase clotting factors and related products more efficiently. From its inception, the Hemophilia Alliance planned to dedicate its discretionary revenue to the bleeding disorders communities.

Toward that end, the Alliance created a grants committee in 2009. Its first task was to establish a process through which the Alliance could channel its discretionary funds to nonprofit organizations that served people with bleeding disorders. The first grants were given out that year; they totaled \$250,000. In 2018, the grant awards totaled \$603,000.

In 2013 the grants committee was incorporated as the Hemophilia Alliance Foundation, and the following year it received its IRS 501(c)(3) tax-exempt certification.

II. Timeline for 2019 Grant Process



Call for Applications; Guidance posted on web site ..	Dec 1, 2018
Applications due	Jan 31, 2019
Decisions made by Foundation Board	Mar 8, 2019
Award letters and checks sent	Mar 22, 2019
Grant-funded year begins	Apr 1, 2019
6-Month Progress reports due	Oct 15, 2019
Final Report due	Mar 15, 2020

III. Purpose of Grants

The Hemophilia Alliance Foundation offers these funds for two purposes: (1) to enable eligible organizations to build capacity in order to achieve their mission; (2) to support direct consumer financial assistance programs in eligible organizations. See examples In Sections V-B and V-E.

IV. Eligibility

A. Types of Applicant Organizations

Grant applications currently are accepted from the following tax exempt organizations:

1. Local consumer-led organizations serving people with bleeding disorders
2. Treatment centers serving people with bleeding disorders
3. Regional coordinating centers for federally-funded hemophilia treatment center networks
4. National organizations not already funded by the Hemophilia Alliance and focused on those with bleeding disorders.



B. Grant Ceiling for 2019

The ceiling for local applicants for 2019 is **\$8,000**. This includes local consumer-led organizations and hemophilia treatment centers. A local consumer-led organization may apply for both project and family assistance support, as long as the total for both is \$8,000 or less. How it is divided is up to the applicant, as long as the total does not exceed \$8,000.

National organizations and the eight federally funded regional coordinating centers may apply for up to **\$10,000** for the 2019 grant period.

C. Criteria for Consideration

To be considered for funding, an organization must meet **all** of the following criteria:

1. It serves people with bleeding disorders, either directly or through its members;
2. It operates under one of these IRS tax exemptions: 501(c)(3) or 170(c)(1) or other nonprofit status approved in advance and in writing by the Alliance Foundation board;
3. It has submitted an application by the deadline, COMPLETE WITH REQUIRED ATTACHMENTS as itemized in Section VII Submission Requirements;
4. The project or service it describes is within the Alliance Foundation's guidelines; and
5. The project or service will be completed in the grant year (April 1, 2019 – March 31, 2020).

V. General Guidelines for All Applicants

A. Types of Grants Considered

Three types of grants will be considered:

1. Projects that strengthen the organization's ability to better serve its constituents;
2. Patient/consumer financial assistance grants; and
3. Regional treatment centers' annual meetings.

B. Examples of Projects that Strengthen an Organization

1. The following are some examples of project grants that strengthen the organization:
 - a. Strategic planning process to focus staff and volunteer efforts;
 - b. Purchasing office equipment to achieve efficiencies, improved communication;
 - c. Publishing or updating a website to promote awareness of services;
 - d. Purchase of software to achieve efficiencies;
 - e. Developing or purchasing educational materials to improve consumer or family or staff knowledge. Developed materials should contain acknowledgement of the Hemophilia Alliance Foundation as the source of funds. **NOTE:** You will be expected to let other eligible organizations copy and use newly developed materials with appropriate credit to the developer.
 - f. Professional education to enhance staff knowledge (e.g., costs to attend conferences, take courses, etc.)
 - g. Patient/consumer education related to their medical condition, and associated emotional and social support.

C. Examples of Personnel Costs Allowed

1. Personnel expenses incurred exclusively for the grant activities will be considered, however the temporary nature of the duties must be made clear in the application. Examples of these expenses may include the costs associated with:
 - a. a data entry person to enter file information into a new digital system
 - b. a consultant to lead a planning process or to develop a web site
 - c. a speaker at a meeting or conference

D. Costs Not Allowed

1. Grant funds will **NOT** be awarded for the following costs:
 - a. Administrative, overhead or indirect costs
 - b. Basic, laboratory, or clinical research or related equipment
 - c. Underwriting or sponsorship of fundraising events
 - d. Recurring costs, such as:
 - i. ongoing salaries of regular staff
 - ii. office rent
 - iii. monthly phone bills for the applicant organization
 - iv. routine program costs

E. Guidelines for Awarding Financial Assistance from HAF Funds

The Hemophilia Alliance Foundation (HAF) funds for financial assistance are intended to address family hardship. Organizations wishing to underwrite consumer attendance at regional and national meetings may use HAF *project* funds, but may not use HAF financial assistance funds.

VI. Guidelines for Project Collaborations

A. Collaboration Projects Are Encouraged

By combining forces, larger projects are possible. If two eligible organizations collaborate on a project, the total available for the project is \$16,000. If more than two organizations collaborate, the total maximum available is \$8,000 times the number of collaborating organizations. **The organization that submits the grant becomes the fiscal agent for the project, and therefore receives and disburses the project funds.**

B. Limit on Submitting both a Collaboration and an Individual Project

Generally speaking, applicants may submit an application as a single entity or in collaboration with another, but not both *if the collaboration uses all the allowable project funds of each partner*. **However**, if the collaboration budget is less than the maximum allowable (\$8,000 x # of partners), one or more of the partners may submit an application for a smaller project as long as the sum of its part of the collaboration and its solo project does not exceed \$8,000.

Example: a consumer-led organization and two treatment centers agree on a collaborative project. The total available to the collaboration is \$24,000. If the two centers budget \$8,000 each for their parts of the collaboration, and the consumer-led entity budgets its part of the effort to be \$4,500, then the collaboration budget is \$19,500. The consumer-led entity could submit separately an application for a project that would not exceed \$3,500.

C Additional Requirement for Collaborative Projects

Applications for collaborative projects must include a letter from each collaborating organization that **is specific about its role in the project** (e.g., “we will recruit participants and our staff will supervise their activities”), and is signed by its Authorized Official.

VII. Submission Requirements

A. Format

See outline in Section IX.

B. Budget

Expenses in the budget must be itemized and justified. **Each major item must be identified; along with the calculation showing how the item’s total was derived.** Put another way, the budget must reflect how the writer came up with each major line item’s total. **See Sample Budget in Appendix C. Failure to itemize and justify proposed expenses will result in a rejection of the application.**

C. Length of Proposal Narrative (not counting required attachments)

Applications may not exceed the following page limits. Brevity is appreciated; please use the fewest words necessary to describe the organization, the needs, the objectives, the budget.

1. Proposals only requesting project funding – maximum 3 pages.
2. Proposals only requesting patient/consumer assistance funding – maximum 2 pages.

3. Proposals for both project and patient/consumer assistance funding - maximum 4 pages.
4. Proposals for a collaborative project – 4 pages.
5. Regional Offices and National organizations – 2 pages.

D. Required Attachments

Applicants must also **include the following attachments with the application**. These attachments will not count against your application page limit. **Applications will not be considered for funding if these required documents are not included:**

1. Copy of the organization's tax-exempt certification from the IRS, also called the IRS Tax Determination letter. This is a document from the federal government, not one from the state. See example in Appendix A.
2. A copy of the organization's W-9. See example in Appendix B.
3. If the application reflects a collaboration, letter(s) from each collaborating partner(s) must be provided **stating the role each partner will play in the implementation**;
4. For patient/consumer assistance programs, attach your criteria or guidelines for granting financial assistance.

NOTE: The Hemophilia Alliance Foundation reserves the right to require additional information as it considers an application.

E. Form of Transmission and Deadline

1. Applications and attachments must be submitted **electronically** to info@hemophiliaalliancefoundation.org
2. Applications must be sent by January 31, 2019, by 11:59 p.m. PST. **Late applications will not be considered.**



F. Filenames: What and Why

Applicants should name their files for submission to the Hemophilia Alliance Foundation with letters identifying the **applicant organization name** followed by an indicator of the content of the file. Here are some examples: HFM-app, HFM-IRS exemption, HFM w9; MMGooley app, MMGooley IRS, MMGooley W9; UCSFapp, UCSF IRS, UCSF W9; etc.

*Why, the reader might ask? Generally one names one's files to make them easy to find in one's directory. From the applicant's perspective, "Hemophilia Alliance Foundation" registers as a distinct name. From the Hemophilia Alliance Foundation's perspective, however, this results in a lot of applications named "Hemophilia Alliance Foundation." Think about it. The application (or progress report, or final report) may arrive attached to an email, but the attachments are then separated from the email; they stand alone in a long list of applicant files. **Make your filenames say who you are, as the sender.***

G. Authorized Signature

1. Applications and letters of collaboration must be signed by the organization's authorized official, that is, the person with the authority to incur obligations on behalf of the organization. Such officials are recognized by their authority to:
 - a. sign contracts on behalf of the organization
 - b. approve the organization's budget
 - c. add or subtract staff

As an example, in consumer-led entities, the Executive Director would sign (or, in the absence of the Executive Director, the President); for an HTC, the Medical Director, Administrative Director or perhaps the Department head would sign.



VIII. Causes for Immediate Rejection of Application

A. Failure to submit all required attachments.

These documents are:

- IRS Certification letter (See example in Appendix A)
- Most recently filed Form W-9 (See example in Appendix B)
- Patient/Consumer Assistance Guidelines (only if applying for Patient/Consumer assistance funds)
- Letter(s) from collaboration partner(s) describing their role in the project.

Please note that the Hemophilia Alliance Foundation will not advise applicants that attachments are missing. Incomplete applications will be rejected immediately.

B. Failure to itemize and justify the budget.

See sample budget in Appendix C

C. Failure to submit application on time.

IX. 2019 Application Format

1. State applicant organization type: Local Chapter/Association/Other, HTC, Regional Office, or National Organization.
2. Contact information
 - a. Name of applicant organization
 - b. Address
 - c. Name of contact person
 - d. Telephone of contact person
 - e. Email of contact person
3. Amount Requested: **\$8,000 maximum total/organization for local consumer-led organizations and hemophilia treatment centers; \$10,000 maximum for national organizations and the eight regional coordinating centers.**
 - a. Amount for project.
 - b. Amount For patient/consumer assistance.
 - c. For collaboration list partners, and how much is included for each.
4. Name and signature of authorized Individual
5. Organization description: **brief** description of mission, geographic service area, # served.
6. **Brief** description of the project and/or patient/consumer-financial assistance you propose. For patient/consumer-family financial assistance programs, attach your criteria or guidelines for awarding assistance.
7. **Brief** description of the need that the project addresses.
8. Concisely state the specific outcomes or measurable objectives of the project.
9. How will you measure the success of the project?
10. How will the project strengthen your organization?
11. Itemized Budget - Format



Item Description & Calculation Detail	\$ Amount
TOTAL	

See Sample Budget in Appendix C

Be sure to include required attachments specified in the Guidance

X. 6-Month Progress Report

Grant recipients are required to submit a progress report on the first six months of operation. The report must follow the format below, and must be submitted electronically to info@hemophiliaalliancefoundation.org by October 15, 2019, at 11:59 PDT.

As you will see below, this form also serves as a **vehicle to request project and budget amendments**, and to request a deadline extension. **These requests should not be made lightly.** The Hemophilia Alliance Foundation Board expects projects to be completed in the grant-year timeline. However, we recognize that unanticipated circumstances may arise, and for this reason we will entertain requests for project, budget, and/or deadline changes.



Failure to submit a Progress Report will result in ineligibility to apply for a grant the following year.

Progress Report Format [maximum length one page]

1. Contact information
 - a. Name of organization
 - b. Name of project
 - c. Amount received
 - d. Name of contact person
 - e. Phone and email for contact person
 - f. Authorized Person's signature
2. Briefly describe the progress of your Hemophilia Alliance Foundation grant project and/or patient/consumer financial assistance.
3. Briefly describe any unanticipated hindrances to the project.
4. Briefly describe your expectations for the project's completion.
5. Do you anticipate having any unused funds from this project?
6. Generally, funds remaining at the end of the grant will be returned to the Alliance Foundation. However, if there were hindrances to the project that were out of your control, you may request an extension of up to six months. Do you anticipate:
 - a. returning unused funds? If so, roughly how much?
 - b. requesting an extension of up to 6 months on the grant's deadline? If so, what is the requested new deadline?



IF YOUR PROJECT HAS BEEN COMPLETED BY OCTOBER 15, 2019, YOU MAY FORGO SUBMITTING A PROGRESS REPORT AND SUBMIT YOUR FINAL REPORT BY OCTOBER 15, 2019.

XI. Final Report

Grant recipients are required to submit a final report after the project's completion. The report must follow the outline below, and must be submitted electronically to info@hemophiliaalliancefoundation.org by March 15, 2020, at 11:59 PDT.



FAILURE TO SUBMIT A FINAL REPORT WILL MAKE THE RECIPIENT INELIGIBLE TO RECEIVE FUNDING FOR SUBSEQUENT YEARS' PROJECTS UNTIL THAT REPORT IS RECEIVED. IF THE RECIPIENT HAS APPLIED FOR AND BEEN AWARDED A GRANT FOR THE FOLLOWING YEAR, THE AWARD CHECK WILL BE HELD UNTIL THE FINAL REPORT IS RECEIVED.

Please note that copies of receipts and other justification of expenses **are not required** in this submission, however it is expected that adequate documentation would be available in the event of an audit. The Hemophilia Alliance Foundation Board reserves the right to conduct a program and financial audit of documents and finances associated with this grant.

Final Report Format [maximum length 2 pages]

1. Contact information
 - a. Name of organization
 - b. Name of contact person
 - c. Phone and email for contact person
 - d. Authorized person's signature
2. Name of project and amount of grant.
3. Objective(s) of the project.
4. Describe how well the proposed objectives were met.
5. Describe how the project strengthened the organization and/or its patients/consumers.
6. Financial report: Please reproduce here the original budget, adding a column showing actual expenses.

Example:

Item	Budgeted	Actual Spent
Consultant for strategic planning \$100/hr for 15 hrs	\$1,500	\$1,500
Laptop computer	750	800
Lunch at strategic planning session for 15 @ \$45 each	675	390
Morning and afternoon snack breaks	200	235
Total	\$3,125	\$2,925

7. Amount, if any, of funds remaining.

XII. Frequently Asked Questions

1. Q. Can I submit a proposal for less than \$8,000 (or less than \$10,000 for national organizations and regional coordinating centers)?
A. Absolutely yes.
2. Q. We will apply for patient/consumer financial assistance funding. For an objective, can we just estimate how many people will ask for help and how much they might need?
A. Yes, that's a good, measurable objective.
3. Q. We are moving to more efficient office space. Would the costs associated with the relocation be acceptable as a grant request?
A. Yes, new furniture, better equipment, even the moving van would qualify. The new rent would not.
4. Q. We want to hire a consultant to assess our operations and help us improve. Would that qualify?
A. Yes, a consultant doing a time-limited project would qualify.
5. Q. Can we apply for both project and consumer financial assistance funds?
A. Yes, as long as you meet the eligibility requirements and follow the guidelines.
6. Q. We didn't use all the dollars we received last year because it was for a camp improvement and camp was already in progress when we received it. We'd like to do the project this spring when the snow melts. Can we?
A. You need to complete a report on last year's award and your progress. If the reason you didn't use it is compelling, you may request an extension and the board may approve the timing change. If not, you can apply for the same project again, and return last year's funds.
7. Q. We are partnering with our HTC to host a Men's Retreat later this year and they sent me their W-9 and 501c3 letter. The letter is a state sales tax exempt letter. Will this suffice?
A. No, but you may not need it at all. We only require the attachments for the organization that is actually applying for the grant, not for the collaborators.
8. Q. Can we send consumers to national meetings using patient/consumer financial assistance grant funds?
A. No, you must use project funds if you wish to subsidize patient/consumer attendance at meetings/conferences.

XIII. Where to Call for Help

You are welcome to call or email the Hemophilia Alliance Foundation Board Chair, Joyce Strazabosco, between 10:00 a.m. and 6:00 p.m. Eastern Time. Here is her contact information:
315-226-2196 (cell) joyce@hemophiliaalliancefoundation.org

Appendix A: Sample IRS Determination Letter

INTERNAL REVENUE SERVICE
P. O. BOX 2508
CINCINNATI, OH 45201

DEPARTMENT OF THE TREASURY

Date:

YOUR NONPROFIT, INC.
P. O. BOX 123
MISSION WAY, CA 95050

Employer Identification Number:
12-3456789
DLN:
123456789910
Accounting Period Ending:
December 31
Public Charity Status:
170(b)(1)(A)(vi)
Form 990 Required
Yes
Effective Date of Exemption
January 3, 2002
Contribution Deductibility:
Yes
Addendum Applies:
No

Dear Applicant:

We are pleased to inform you that upon review of your application for tax exempt status we have determined that you are exempt from Federal income tax under section 501(c)(3) of the Internal Revenue Code. Contributions to you are deductible under section 170 of the code. You are also qualified to receive tax deductible bequests, devises, transfers or gifts under section 2055, 2106 or 2522 of the Code. Because of this letter could help resolve any questions regarding your exempt status, you should keep it in your permanent records.

Organizations exempt under section 501(c)(3) of the Code are further classified as either public charities or private foundations. We determined that you are a public charity under the Code section(s) listed in the heading of this letter.

For important information about your responsibilities as a tax-exempt organization, go to www.irs.gov/charities. Enter "4221-PC" in the search bar to view Publication 4221-PC, Compliance Guide for 501(c)(3) Public Charities, which describes your recordkeeping, reporting, and disclosure requirements.

Sincerely,

Ms. Mission

Director, Exempt Organization

Letter 111

This document is a sample for the sole purpose of displaying what an IRS determination letter looks like. This is not an actual determination letter. The use of this document is intended strictly for informational purposes and not any commercial purpose. This document is not for sale.

Appendix B: Sample Blank W-9 Form

Applications must include a copy of the organization's current W-9.

Form W-9 (Rev. October 2007) Department of the Treasury Internal Revenue Service	Request for Taxpayer Identification Number and Certification	Give form to the requester. Do not send to the IRS.
Print or type See Specific Instructions on page 2.	Name (as shown on your income tax return)	
	Business name, if different from above	
	Check appropriate box: <input type="checkbox"/> Individual/Sole proprietor <input type="checkbox"/> Corporation <input type="checkbox"/> Partnership <input type="checkbox"/> Limited liability company. Enter the tax classification (D=disregarded entity, C=corporation, P=partnership) ▶ <input type="checkbox"/> Exempt payee <input type="checkbox"/> Other (see instructions) ▶	
	Address (number, street, and apt. or suite no.)	Requester's name and address (optional)
	City, state, and ZIP code	
List account number(s) here (optional)		

Part I Taxpayer Identification Number (TIN)

Enter your TIN in the appropriate box. The TIN provided must match the name given on Line 1 to avoid backup withholding. For individuals, this is your social security number (SSN). However, for a resident alien, sole proprietor, or disregarded entity, see the Part I instructions on page 3. For other entities, it is your employer identification number (EIN). If you do not have a number, see *How to get a TIN* on page 3.

Note. If the account is in more than one name, see the chart on page 4 for guidelines on whose number to enter.

	Social security number
	: : : : : : : : :
	or
	Employer identification number
	: : : : : : : : :

Part II Certification

Under penalties of perjury, I certify that:

- The number shown on this form is my correct taxpayer identification number (or I am waiting for a number to be issued to me), and
- I am not subject to backup withholding because: (a) I am exempt from backup withholding, or (b) I have not been notified by the Internal Revenue Service (IRS) that I am subject to backup withholding as a result of a failure to report all interest or dividends, or (c) the IRS has notified me that I am no longer subject to backup withholding, and
- I am a U.S. citizen or other U.S. person (defined below).

Certification instructions. You must cross out item 2 above if you have been notified by the IRS that you are currently subject to backup withholding because you have failed to report all interest and dividends on your tax return. For real estate transactions, item 2 does not apply. For mortgage interest paid, acquisition or abandonment of secured property, cancellation of debt, contributions to an individual retirement arrangement (IRA), and generally, payments other than interest and dividends, you are not required to sign the Certification, but you must provide your correct TIN. See the instructions on page 4.

Sign Here	Signature of U.S. person ▶	Date ▶
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General Instructions

Section references are to the Internal Revenue Code unless otherwise noted.

Purpose of Form

A person who is required to file an information return with the IRS must obtain your correct taxpayer identification number (TIN) to report, for example, income paid to you, real estate transactions, mortgage interest you paid, acquisition or abandonment of secured property, cancellation of debt, or contributions you made to an IRA.

Use Form W-9 only if you are a U.S. person (including a resident alien), to provide your correct TIN to the person requesting it (the requester) and, when applicable, to:

- Certify that the TIN you are giving is correct (or you are waiting for a number to be issued),
- Certify that you are not subject to backup withholding, or
- Claim exemption from backup withholding if you are a U.S. exempt payee. If applicable, you are also certifying that as a U.S. person, your allocable share of any partnership income from a U.S. trade or business is not subject to the withholding tax on foreign partners' share of effectively connected income.

Note. If a requester gives you a form other than Form W-9 to request your TIN, you must use the requester's form if it is substantially similar to this Form W-9.

Definition of a U.S. person. For federal tax purposes, you are considered a U.S. person if you are:

- An individual who is a U.S. citizen or U.S. resident alien,
- A partnership, corporation, company, or association created or organized in the United States or under the laws of the United States,
- An estate (other than a foreign estate), or
- A domestic trust (as defined in Regulations section 301.7701-7).

Special rules for partnerships. Partnerships that conduct a trade or business in the United States are generally required to pay a withholding tax on any foreign partners' share of income from such business. Further, in certain cases where a Form W-9 has not been received, a partnership is required to presume that a partner is a foreign person, and pay the withholding tax. Therefore, if you are a U.S. person that is a partner in a partnership conducting a trade or business in the United States, provide Form W-9 to the partnership to establish your U.S. status and avoid withholding on your share of partnership income.

The person who gives Form W-9 to the partnership for purposes of establishing its U.S. status and avoiding withholding on its allocable share of net income from the partnership conducting a trade or business in the United States is in the following cases:

- The U.S. owner of a disregarded entity and not the entity,

Appendix C: Sample Itemized Budget

Item	\$ Amount
Personnel , for example	
Strategic Planning Consultant @ \$100/hr for 9 hrs	\$900.00
Data entry person @ \$15.00/hr for 80 hrs	\$1,200.00
Honorarium for 2 conference speakers @ \$100/speaker	\$200.00
Equipment for example:	
1 desktop HP computer	\$450.00
1 small desk	\$175.00
1 desk secretarial chair	\$125.00
Supplies for example:	
10 10-packs of pocket folders @ 7.50/10-pack	\$75.00
1 5-pack Zapdos 32GB Flash Drive @ \$36.99/5-pack	\$36.99
Travel for example	
Round trip air fare for 4 staff @ \$575 each	\$2,300.00
Mileage reimbursement at \$.55/mile for 330 miles	181.50
Parking for 50 participants at \$15/participant	750.00
Tuition/Registration	
Registration for 2 consumers at \$80/person	\$160.00
Registration for 2 nurses @ 175/person	350.00
Consumer financial assistance for example	
Awards averaging \$100 for up to 10 patient/consumer families	\$1,000.00
Other	
Extended warranty for computer	\$100.00
Total Expenses	\$8,003.49
Total Amount Requested	\$8,000.00