



## 2024 Project/Patient Assistance Grant Guidance

### IMPORTANT DATES

Call for Applications; Guidance posted on website.....	Dec 1, 2023
Applications due .....	Jan 31, 2024
Decisions made by Foundation Board .....	Mar 8, 2024
Award letters and checks sent .....	Mar, 2024
Grant-funded year begins .....	Apr 1, 2024
6-Month Progress reports due .....	Oct 15, 2024
Grant-funded year ends .....	Mar 31, 2025
Final Report due .....	Apr 15, 2025

**Please use the following checklist to ensure required documents are included with your application**

- Your organization’s federal tax-exempt certification from the IRS, also called the IRS Tax Determination letter or 501(c)(3).
- A copy of your organization’s W-9.
- If the application reflects a collaboration, the following **MUST** be included: 1) a letter(s) from *each* collaborating partner(s) **stating the role each partner will play in the implementation**, and 2) *each* organization’s federal tax-exempt certification letter from the IRS or 501(c)(3).
- For patient/consumer assistance programs, attach your criteria or guidelines for granting financial assistance.
- Detailed budget with justification.

**ALL GRANTS ARE SUBJECT TO THE AVAILABILITY OF FUNDS. THE HEMOPHILIA ALLIANCE FOUNDATION RESERVES THE RIGHT TO REDUCE GRANT AMOUNT REQUESTS.** Funds provided under this application may not be used for other purposes.

## **Purpose of Grants**

The Hemophilia Alliance Foundation (HAF) offers these funds for two purposes: (1) to enable eligible organizations to build capacity in order to achieve their mission; and (2) to support direct consumer financial assistance programs via eligible organizations.

## **Eligibility**

### **Types of Applicant Organizations**

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

- Local consumer-led organizations serving people with heritable bleeding & thrombotic disorders
- Federally funded hemophilia treatment centers serving people with bleeding disorders
- The 8 Maternal & Child Health Bureau and CDC federally designated and funded regional hemophilia core centers for partial funding of their respective regional meetings
- National organizations focused on persons with heritable bleeding disorders. Although the National Bleeding Disorders Foundation is not eligible for funding, its national chapters are eligible

### **Criteria for Consideration**

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

- It operates under one of these IRS tax exemptions: 501(c)(3) or 170(c)(1) or other nonprofit determination status
- It is not delinquent at the time of the grant submission for any outstanding previous HAF six-month or final grant reports. It has no outstanding unreturned unspent funds from previous HAF grants that were not returned as requested. If in doubt, please contact [Audra@hemophiliaalliancefoundation.org](mailto:Audra@hemophiliaalliancefoundation.org).
- It has submitted an application by the deadline, **COMPLETE WITH REQUIRED ATTACHMENTS**
- The project or service it describes is within HAF's guidelines
- The project or service will be completed within the grant year (April 1, 2024 – March 31, 2025)

## **General Guidelines for All Applicants**

### **Types of Grants Considered**

Three types of grants will be considered:

- Projects that strengthen the organization’s ability to better serve its constituents
- Patient/consumer financial assistance grants
- Regional hemophilia treatment centers’ annual meetings

## Grant Ceiling for 2024

The ceiling for local chapters, hemophilia treatment centers, and associations for 2024 is **\$8,000**. This includes local consumer-led organizations. Local chapters and consumer-led organizations may apply for both *project* and *patient/family assistance support*, as long as the total for both is \$8,000 or less. How it is divided may be determined by the applicant, as long as the total does not exceed \$8,000. National organizations and the eight HHS-designated federally funded regional core coordinating centers may apply for up to **\$10,000** for the 2024 grant period.

## Grant Scoring

The HAF Board scores project grants on the following criteria:

- How well the applicant describes how the project will improve the lives of persons with bleeding and thrombotic disorders
- The description of the organization’s mission, purpose, impact, and number of patients served
- A well-described need for funding
- Appropriateness and clarity of the project’s SMART objectives
- How well the project will strengthen the organization
- The clarity and completeness (with narrative) of the budget.

## Suggestion of Types of Projects Designed to Strengthen an Organization

- Proposing a strategic planning process to focus staff and volunteer efforts
- Purchasing office equipment to achieve efficiencies, and improve communication
- Publishing or updating a website to promote awareness of services
- Purchasing software to achieve efficiencies
- Developing or purchasing educational materials to improve consumer or family or staff knowledge. Developed materials should contain acknowledgement of the HAF 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.**
- Professional education to enhance staff knowledge (e.g., costs to attend conferences, take courses, etc.)
- Patient/consumer education related to the patient’s/family’s medical condition and associated emotional and social support

### NOTE:

- Requests for travel funds to send patients/families to regional or national meetings should be included as part of the *project award budget*, **not** as patient financial assistance.

- Recurring costs related to programs such as bleeding disorder camps, other educational programs, and outreach clinics are allowed.

## Objectives

Please write all objectives for the project using SMART format (specific, measurable, attainable, realistic, and timely). Consideration for funding will be affected if objectives are not written clearly.

For a short guide to “Developing Program Goals and Measurable Objectives”. Click on link:

### [Developing Program Goals and Measurable Objectives](#)

Additional guidance on writing SMART Objectives is available as a YouTube video. Click on link:

### [Soft Skills – Setting SMART Goals](#)

## Personnel Costs Allowed

For **project grants**, personnel expenses **up to but not exceeding 25% of total project grant request** and incurred exclusively for the grant project activities will be considered. These may include:

- Part-time data entry person to enter file information into a new digital system
- Program manager who may create, deliver, and/or evaluate the program
- Nurse or physical therapist who may be facilitating the program/activity

NOTE: Consultants and speakers (for example at a meeting or conference) are NOT considered personnel and therefore should NOT be counted toward personnel

For **patient assistance grants**, personnel expenses **up to but not exceeding 10% of the total patient assistance grant request** may be included for the purpose of administering patient assistance funds.

## Costs Not Allowed

Grant funds will **NOT** be awarded for the following costs:

- Overhead or indirect costs (institutional or organizational costs to administer the grant)
- Clinical or laboratory-based research projects or related costs
- Underwriting or sponsorship of fundraising events
- Recurring costs, such as office rent/utilities; monthly phone bills for the applicant organization; salaries of staff for time not related to the application project.
- Purchase of promotional items. Promotional items include branded giveaways that do not directly contribute to the program goals. Branded items, such as supplies, with a specific programmatic purpose are permitted. Example:

Purchase of notepads and ballpoint pens with the organization's logo to facilitate note taking at an educational event would be permissible. If in doubt, please contact [Audra@hemophiliaalliancefoundation.org](mailto:Audra@hemophiliaalliancefoundation.org).

## Guidelines for Awarding Patient Assistance from HAF Funds

The HAF funds for patient financial assistance are intended to address family hardship. It is **REQUIRED** that you include your organization's *patient assistance policy*. [Click here for a policy example](#).

The patient assistance policy must include the following criteria:

- Eligibility criteria
- Explanation of how funds are distributed
- Process of approval and/or qualifying entity(s) of approval
- Application process for eligible consumers
- Patient assistance policy must be dated with the approval date by the organization

**NOTE:** To simplify the request for **patient assistance funds**, the portion of the grant requesting such funds does **NOT** require completion of the following grant application sections: (8) *Objectives/Outcomes*; (9) *Measurement of success of project*; (10) *How the project will strengthen the organization*. However, in the *budget narrative* you **MUST** estimate the number of patients/families expected to be helped by these funds and the average amount of funds per patient/family.

## 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.** The budget must reflect how the applicant arrived at each major line item's total. **Failure to itemize and justify proposed expenses will result in a rejection of the application.** [Click here to see budget example](#).

**Personnel expenses** for the project grant and personnel expenses for the patient assistance grant should be listed as **SEPARATE LINE ITEMS** in the budget. Clearly identify the individual(s) who will be performing these grant-related activities in the budget narrative.

## Project Collaborations

### Collaboration Projects Are Encouraged

By combining forces, larger projects are possible. If two grant-eligible organizations collaborate on a project, the total funds available for the project are \$16,000. The maximum award available for collaborative projects **may not exceed \$24,000**. **The organization that submits the**

**grant becomes the fiscal agent for the project, and therefore receives and disburses the project funds.**

In general, collaborating institutions should *function separately* and be *financially separate* with separate Employer (or Taxpayer) Identification Numbers (EIN/TIN). If grant applicants intend to submit a collaborative project, but are unsure of their eligibility as collaborating organizations, please contact [Audra@hemophiliaalliancefoundation.org](mailto:Audra@hemophiliaalliancefoundation.org) for board approval.

**REMEMBER:** If the application reflects a collaboration, the following **MUST** be included:

- A copy of the submitting organization's W-9 (only the fiscal agent's organization needs to submit their W-9).
- A letter(s) from *each* collaborating partner(s) **stating the role each partner will play in the implementation** (e.g., "we will recruit participants and our staff will supervise their activities") and is signed by its Authorized Official, and
- **Each organization's** federal tax-exempt certification letter from the IRS or 501(c)(3).

### **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 qualified entity, 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 budget 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 \$20,500. The consumer-led entity could separately submit an application for a project that would not exceed \$3,500.*

### **Required Attachments**

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

- Copy of the organization's federal tax-exempt certification from the IRS, also called the IRS Tax Determination letter or 501(c)(3). For collaborative projects **each collaborating organization** must submit a copy of their federal tax-exempt certification letter.
- A copy of the organization's W-9. For collaborative projects, **only the fiscal agent's organization** must submit a copy of their W-9.
- 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**. This *letter of collaboration* is **required** for each tax-exempt eligible collaborating organization that is receiving funds for the submitted project.

- A *letter of support* is **highly recommended** from an organization or entity whose participation in the project is critical but is not a collaborating partner, that is, **not receiving funding directly from the project's budget**. For example, if funds are requested to partially support the purchase of portable ultrasound equipment to be used by a physical therapist in hemophilia clinic, a letter of support from the physical therapy department stating their commitment to appropriately train a physical therapist in its use would be important to include with the project application.
- For patient/consumer assistance programs, attach your organization's policy for granting financial assistance.

**NOTE: The HAF reserves the right to request additional information as it considers an application.**

## Form of Transmission and Deadline

Applications will be available online on the Foundation website as of December 1, 2023. **Applications are to be filled out online and submitted online by pressing the SUBMIT button on the bottom of the application form.** Attachments must be submitted electronically by attaching them to the application. Applicants will receive an electronic acknowledgement that their application has been received. **IF YOU HAVE NOT RECEIVED AN ACKNOWLEDGEMENT OF RECEIPT, IT MEANS THAT YOUR APPLICATION MAY HAVE NOT BEEN RECEIVED.** Please contact [Audra@hemophiliaalliancefoundation.org](mailto:Audra@hemophiliaalliancefoundation.org) if you do not receive this acknowledgement.

**Application submissions are due January 31, 2024.**

## Authorized Signature

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:

- Sign contracts on behalf of the organization
- Approve the organization's budget
- Add or subtract staff

Please note that in general, an HTC director within a larger institution is NOT authorized to sign contracts on behalf of the organization. If in doubt, check with your institution's grants management office or financial officer.

## Causes for Immediate Rejection of Application

### **Failure to submit all required attachments.**

These documents are:

- Federal tax-exempt certification letter
- Most recent W-9
- Patient/Consumer Assistance Guidelines (if applying for Patient/Consumer assistance funds)
- For collaboration projects, a letter(s) must be submitted from each collaborating partner(s) describing their role in the project.
- For collaboration projects, each collaborating partner must submit their own federal tax-exempt certification letter
- For collaboration projects, only the responsible (submitting) fiscal agent needs to submit their most recent W-9

Please note that the HAF will not be responsible for advising applicants that attachments are missing.

**Failure to itemize and justify the budget.**

**Failure to submit the application on time.**

**Missing reports or failure to return unused funds from a previous HAF grant cycle.**

## **EXAMPLES OF SUCCESSFUL GRANTS**

Click [here](#) for examples of previous successful grants.

**A 6 Month Progress report will be due October 15, 2024 on the HAF website. IF YOUR PROJECT HAS BEEN COMPLETED BY OCTOBER 15, 2024, YOU MAY FORGO SUBMITTING THE PROGRESS REPORT AND INSTEAD SUBMIT YOUR FINAL REPORT BY OCTOBER 15, 2024.**

**Final report due April 15, 2025 on the HAF website.**

## **Frequently Asked Questions**

- 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.
- 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. Although the patient assistance portion of the grant no longer requires written objectives or measurement of success, it is requested that the budget narrative estimate the



number of patients/families expected to be helped and the average amount of funds per patient/family.

- 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 cost would qualify. The new rent would not, because it is a continuing expense.
- 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. Note that consultants are NOT considered personnel and therefore their cost should NOT be counted toward personnel costs.
- Q. Can we apply for both project and consumer financial assistance funds?
- A. Yes, as long as you meet the eligibility requirements, follow the guidelines, and do not exceed the maximum \$8,000 award total (\$10,000 for National organizations and the eight HHS-designated federally funded regional core coordinating centers).
- 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. In general, the maximum limit for extensions is 6 months. If the project cannot be completed at that time, unspent funds should be returned to HAF. You can consider applying for the same project again, for the subsequent year.
- Q. We are partnering with our HTC to host a Men's Retreat later this year and they sent me their state sales tax exempt letter. Will this suffice?
- A. No. For collaborative projects we require the federal tax-exempt certification letter from the IRS *from each of the collaborating partners* that are applying for the grant. A state sales tax exempt letter will not suffice.
- 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. The use of patient financial assistance grant funds to reimburse patients/families for the cost of travel to or from the treatment center for treatment or a comprehensive visit is permissible.
- Q. We won't be able to complete our project before the deadline. Can we get an extension?
- A. HAF Board expects projects to be completed in the grant-year timeline. However, we do recognize that unanticipated circumstances may arise and requests for project, budget, and/or deadline changes may be considered. You can request an extension on your 6-month progress report. Remember that, in general, the maximum limit for extensions is 6 months. If the project cannot be completed at that time, unspent funds should be returned to HAF.

- Q. Our grant was to fund our annual meeting or a community event, but we had to cancel the event. Can we use our funds for something else?
- A. HAF will consider project changes if circumstances don't allow for the original project to be executed, as long as the changes fit within the scope of the original grant and the goals remain similar. Otherwise grant funds would need to be returned to HAF. Send your requests for project changes to [info@hemophiliaalliancefoundation.org](mailto:info@hemophiliaalliancefoundation.org) or [audra@hemophiliaalliancefoundation.org](mailto:audra@hemophiliaalliancefoundation.org) and the board will review and decide.
- Q. Our medical center has separate pediatric and adult hemophilia treatment centers. Can the centers submit a collaborative project grant for \$16,000 (\$8,000 each)?
- A. In general, the answer to this question is "No." Collaborating eligible institutions must function separately and be financially separate with separate Employer (or Taxpayer) Identification Numbers (EIN/TIN). If you are in doubt, please email the HAF Board Chair, Michael Craciunoiu, at [chair@hemophiliaalliancefoundation.org](mailto:chair@hemophiliaalliancefoundation.org).
- Q. Our HTC staff also supports the Sickle Cell Center at our institution. Our HTC would like to include the patients from the Sickle Cell Center with our bleeding disorder patients in an educational activity about methods of pain relief. Can we include the cost of attendance at the educational event for sickle cell patients in our HAF grant budget?
- A. In general, HAF patient assistance/project grants do not currently include sickle cell centers as eligible entities. However, HAF does encourage eligible HTCs in which their staff members also care for sickle cell patients to consider including these patients, if appropriate, in the capacity building activities included in their HAF grant. The HTC as the eligible entity must be the applying entity and must be the responsible party for implementing the grant.

For questions or assistance, please email the HAF Board Chair, Michael Craciunoiu, at [chair@hemophiliaalliancefoundation.org](mailto:chair@hemophiliaalliancefoundation.org).