



PACT FOUNDATION

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July 27, 2017

Dear Chapter/Association:

I am pleased to announce that Shire will once again sponsor the PACT State Advocacy Grant Program. It is open to all local hemophilia organizations that have now, or are initiating a state based advocacy program.

The application and informational packet are enclosed. Previous year grant recipients submitted stellar projects. The feedback and progress that has occurred, as a result of these grants, has been outstanding.

I hope you will take the opportunity to review the enclosed material carefully, and apply if possible. You will receive a confirmation when we have received your proposal.

I look forward to hearing from you.

Sincerely,



Elena Bostick
PACT Coordinator

EB/gc
Enc.

P.S. Please email completed proposal including attachments to:

[hemnj@comcast.net](mailto:hemn@comcast.net)

OR

If submitting by US mail, please include 1 original
and 2 copies

Purpose of the PACT Program

Over the past several years hemophilia consumers and providers have had serious concerns regarding the changing health care environment. At issue has been the need to maintain quality care for all persons affected by hemophilia. The rapidly changing marketplace has raised questions about the future of hemophilia care and patient access to the full range of needed products and services including access to the appropriate specialty providers who offer them. The challenge is to preserve policies and programs that ensure patient access.

It has become apparent that aggressive, state-based advocacy offers the greatest opportunity to identify and respond to potential threats and opportunities. In 2005 Baxter BioScience (which was spun off to Baxalta and now a part of Shire) agreed to fund a pilot program which would support state advocacy initiatives that are geared toward maintaining and/or expanding access to high quality care for persons with hemophilia. To date 101 grants have been awarded for a total of nearly \$2.2 million.

For example, some previously submitted PACT projects sought to:

- Protect access to medicine and services through state legislation.
- Conduct grassroots advocacy campaigns, directed at key decision makers, in an effort to preserve quality of care.
- Provide a specific and valuable resource to consumers, individually, to help them maintain access.

ELIGIBLE GRANT EXPENSES

Eligible Grant Expenses include, but are not limited to

- * Partial Staff Salaries: As required to execute grant proposal, may include salary expenses for new staff, or to expand the role of existing staff.
- * Consultant Services: lobbyist, health insurance consultant, attorney, etc.
- * Travel and Lodgings: Mileage/airfare to cover legislative and agency visits.
- * Printing and Production: Creation of background materials or newsletter that provides information and guidance regarding policy initiatives.
- * Web Site: Costs associated with the creation and timely maintenance of a web site that supports a specific advocacy need associated with access to care.
- * Conference and Workshop Fees: Funding to attend workshop and meetings associated with a specific area of advocacy.

PACT State Advocacy Grant Proposal Criteria

- 1) Proposed project must pertain to a specific program of state advocacy, either current or proposed, to be conducted by the applicant.
- 2) Proposed project must define:
 - a) Number of persons with Hemophilia in your Chapter's/Association's area
 - b) An identified problem
 - c) Methodology to address problem
 - d) Anticipated outcome
 - e) Budget (Must identify specific dollar amounts allocated to PACT Grant funding)
- 3) Each proposal must be original. Proposals that duplicate another Chapters submission will not be considered.
- 4) More than one proposed project may be submitted for consideration from an individual chapter or association, or from multiple organizations in a state. Projects must be defined individually for each application submitted.
- 5a) Multi-year requests may be submitted but will be considered one year at a time, and must specify intermittent goals and benchmarks. Subsequent year funding is not assured. If a proposal has been funded in previous years please describe any progress that has been made toward achieving the goal of the initiative and/or any revisions in the initiative or environmental changes that will lead to a successful outcome.
- 5b) All grantees will be required to complete and submit a mid-year progress report by June 2018. Failure to do so will exclude renewal applications from consideration.

Progress report shall include:

- Progress/achievements to date
 - Barriers encountered
 - Itemized use of budget to date
- 6) Additional consideration will be given to proposals that demonstrate sustainability of the effort by leveraging resources beyond the grant itself. These resources may be additional funding, in-kind contributions, or both.

Additional consideration will also be given to projects that identify a specific state advocacy target, complete with goals/outcomes.

- 7) Additional consideration will also be given to proposals that address a broad based concern and indicate how the project could be replicated in other states.**
- 8) Applicant must possess certification of tax-exempt status.
- 9) Maximum funding request, per project is \$25,000. No more than \$5,000 of the total grant may be attributed to a single event such as a legislative day or advocacy training.
- 10) Applications must be received on or before the deadline date of **September 29, 2017.**
- 11) Letters of support from HTC's, State Departments of Health or other Community-based organizations are helpful, but not required.

Proposal Outline

Agency Data (Include Mailing Address)

Agency Official

Title _____

Statement of the Problem

Proposed Methods of Accomplishment

Evaluation Procedure

Budget, including additional anticipated resources if any

Attachments

- a. Certification of non-profit tax except status
- b. Officers and Directors' list
- c. Letter of support
- d. Copy of year-end financial statement

PACT Grant Review Committee

Eligible grantees will be selected by a committee of individuals who have been chosen for their experience in hemophilia advocacy and/or government policy. All attempts have been made to create a committee whose members are diverse in areas of expertise and regional representation. Committee members may not have any conflict of interest that might interfere or cast doubts on their selection of eligible grantees. Conflicts of interest include, but are not limited to, employment by a manufacturer or distributor of clotting factors.

**The PACT Foundation retains the right to publish, or otherwise share the text of funded proposals and progress reports with other state hemophilia chapters and organizations. This material is viewed as a tool intended to encourage similar advocacy activity.