

**CSL Behring Foundation for Research and Advancement of Patient Health
GRANT APPLICATION FORM**

Please type or print clearly, including the following specified information.

Organization Information

Name of Organization: World Federation of Hemophilia USA
Contact person/applicant and title: Miklos Fulop, Secretary/Treasurer
(please limit to one)

Address: c/o WFH USA, 1425 Rene Levesque Blvd. W.
Suite 1010, Montreal, Canada, H3G 1T7
q 1-877-417-7944
Fax: 1-514-875-8916
E-mail: info@wfhusa.org
Tax ID/SSN: 16-1513923
Grant Category: (Select ONE)
*? Research Grant x Patient Grant ? Small Community-Based Unrestricted Grant**
**Unrestricted Grants are reviewed yearly during the 2nd granting cycle only.*

Proposed Project (this section should not exceed 3 pages)

Describe proposed project, including identification of needs/problems to be addressed and target population(s). Please limit the description to 500 words. If you wish to include further supporting information please include this as an attachment, for example if this is a request for a research/scientific grant you should attach a more detailed description of study design and methodology, etc.

**The audience gasped when pictures of children's ankles
and knee joints appeared on screen**

Last February, the World Federation of Hemophilia USA (WFH USA) gave a presentation at a meeting of hemophilia organization leaders in Arizona. The photos of children with hemophilia living in developing countries shocked the audience. Not many in the U.S. hemophilia community are aware of the dire issues affecting their counterparts abroad. Many, once learning about the global hemophilia community, want to help but don't know how.

WFH USA is 501(c)(3) charity that builds awareness and support for the need to improve treatment for all people with bleeding disorders, no matter where they live. In the developing world, the vast majority of children and adults with hemophilia remain untreated. They suffer from crippling pain and disability. Too



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many die young. Even if they survive, they face the threat of acquiring infectious blood-borne diseases, such as HIV. The statistics are discouraging – one in three people treated for hemophilia has hepatitis C and one in 10 has HIV. The infusion of even small amounts of safe blood treatment products will significantly boost life prospects. That’s why the WFH USA’s work is so important.

Last year, WFH USA received a \$10,000 grant from CSL Behring Foundation that enabled us to develop our first website, www.wfhusa.org. Your grant also allowed us to produce, print, and mail *Hemophilia Aid*, an information-packed newsletter distributed to more than 1,000 key leaders in the hemophilia community. As a follow-up, we conducted considerable outreach. We held consultations with hemophilia clinic directors and with patient group leaders on how to reach out their patients. We have also discussed with the National Youth Leadership Institute on how to get more youth interested in hemophilia issues at a global, national and regional level. Out of these consultations, two simple ideas came forth:

- Produce a series of ready-to-use promotional materials that can be mailed with, placed in, or adapted to existing communication vehicles of hemophilia organizations, treatment centers, and homecare companies. These promotional materials will be informative and inspire families with hemophilia throughout the U.S. to get involved in our cause.
- Inform the hemophilia community about American volunteers who are already making a difference to the lives of others in poor countries.

With the support of CSL Behring Foundation, we can accomplish this important awareness-building and education project.

Describe project goals / anticipated outcomes including measurement criteria, for example anticipated attendance, number of new patients expected to be identified, or study objectives.

Treatment for All: Public Awareness and Education Project

Project goals	Activities	Anticipated outcomes	Measurement criteria
Build awareness of the global hemophilia community	<ol style="list-style-type: none"> 1. Create series of profiles of U.S. international volunteers 2. Create general information pamphlet about hemophilia abroad 3. Develop a series of advertisements 4. Seek promotional opportunities through patient groups, hemophilia treatment centers and homecare companies 	Increased appreciation of the U.S. role in international hemophilia development; increased awareness of hemophilia in a global context; and increased interest and involvement in WFH USA’s mission; and increased in donations.	<ul style="list-style-type: none"> # of chapter presentations made by WFH USA # of telephone inquiries received # of website visitors # of new volunteers # of special event participants # of donors Amount of funds raised

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GRANT APPLICATION FORM**

Please provide an implementation plan and timetable.

Activities	Implementation plan	Timetable
1. Create series of profiles of U.S. international volunteers	Secure services of professional writer/photographer Contact U.S. volunteers of WFH and seek their permission to be profiled in the promotional campaign Write/edit feature stories Pitch stories to patient organizations and to relevant local and regional media Monitor coverage	October 2007 October 2007 October 2007 November 2007 – December 2008 November 2007 ongoing
2. Create general information pamphlet about hemophilia abroad	Contact HTC's, homecare companies and patient groups to confirm the quantity of pamphlets needed Secure services of full-service ad/graphic design agency Select design concept Write/edit copy Hand-out pamphlets at NHF Annual Meeting/Take orders of pamphlets Send out pamphlets to HTC's, homecare companies and patient groups Monitor mail for pamphlet's bounce-back cards Conduct telephone follow-up with HTC's, homecare companies and patient groups	October 2007 October 2007 October 2007 November 2007 November 2007 – December 2008 November 2007 ongoing November 2007 ongoing
3. Develop an advertorial series	Contact patient groups to confirm their desire to feature advertorial series Secure services of full-service ad/graphic design agency Select design concept Write/edit copy Hand-out advertorials at NHF Annual General Meeting/take orders Send advertorials to patient groups and place on WFH USA website Monitor website hits Obtain clippings from patient groups	October 2007 October 2007 October 2007 October 2007 November 2007 November 2007 – December 2008 November 2007 onwards November 2007 onwards
4. Seek promotional opportunities with families with hemophilia through patient groups, hemophilia treatment centers and homecare companies	Create a Powerpoint presentation Seek opportunities for WFH USA presentations Develop PR kit for HTC's and patient groups who already participate in international hemophilia development to promote their work to their local /state community & media Liaise with these HTC's and patients groups to maximize their media exposure in local/state community Obtain media clippings from patient groups	October 2007 October 2007 ongoing January 2008 January 2008 – December 2008 January 2008 – December 2008

Identify whether the project is a new or continuing program and provide justification to support this.

WFH USA's mission is to build awareness and raise funds in support of our global mission to ensure treatment for all people with bleeding disorders. The proposed public awareness project marks a *new* phase of our engagement with the hemophilia community. Prior to this phase, we focused on standard communication vehicles – the *Hemophilia Aid* newsletter and our website – to frame our international work. Although many leaders within the community became apprised of our existence, the

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GRANT APPLICATION FORM

vast majority of people with hemophilia have yet to be touched by our message. We seek CSL Behring Foundation's support of a new, broader community engagement project aimed at families with hemophilia and patient groups. With your support, we will inspire people to make a real difference to the lives of others struggling with the hemophilia abroad.

If applicable, please comment upon your project's potential to serve as a model program locally and/or nationally.

The proposed public awareness and education project may serve as a model to motivate families with hemophilia to become more active in bleeding disorder issues.

The decline in volunteer engagement has been of concern to both local and national hemophilia patient groups. Opening the eyes of the families with hemophilia and patient groups to the challenges faced by their counterparts abroad may serve as a strong motivator to keep active and involved.

Community groups and faith communities, such as the Episcopalian and Catholic, have engaged their local parishes in "think global, act local" and have seen their community engagement grow as a result (For example, visit www.globalgood.org or www.crs.org). Furthermore, with mass media focused on international causes of Hollywood celebrities, it is a perfect time to spur people with hemophilia to help others in their global community and thereby inspire them to volunteer locally as well.

If the project significantly involves other organizations / individuals please ensure the application includes letters of support from them.

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Budget

Please detail your total budget request, including a line item breakdown for all costs. Provide justification for large or unusual expenditures. Institutional overhead, and indirect and administrative expenses should be included and limited to 10%. Any travel must be the lowest applicable coach-class fare. Any salary requests of currently funded staff should be addressed as to the necessity of additional funding from the Foundation.

Please include any details of supplemental funding sources from any other corporate or Foundation supporters and, if applicable, level of support and respective role(s) from additional funding sources.

Note: Poor justification may lead to reduction in the awarded grant or the application to be rejected.

Treatment for All: Public Awareness and Education Project Budget: October 2007 – December 2008			
	Quantity	Total Costs	Explanation
Revenue			
CSL Behring Foundation		30,000	Pending
TOTAL REVENUE			
Expenses			
	Quantity	Total Costs	
Creative Services			
Writer/Photographer (at least 5 volunteer profiles)	1	4,500	
Powerpoint presentation	1	500	
Advertising/graphic design	1	6,500	
Printing & Supplies			
General information pamphlet	10,000	7,000	
Advertorials (series of 5)/Volunteer Profiles	750	750	To be mailed to patient groups, HTCs and homecare companies; pdf copies will also be available
PR Kit for HTCs	100	300	To be used by HTCs involved in international development to send to local/regional media
Signage (NFH Booth, patient group presentations)	3	200	
Postage			
Shipping/courier		2,250	Bulk shipping of information pamphlet to patient groups, homecare companies and HTCs
Travel			
Travel to patient groups, volunteer profiles		5,000	Estimated 8 round-trips, economy fare
Overhead/Administration			
		3,000	
TOTAL		30,000	

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Attachment Requests

Please include a copy of the organization's most recent 501(c)(3) U.S. Internal Revenue Service letter if applicable and you have not sent this to us with a prior application. This may be sent separately from your electronic application, however please indicate that it is being sent by post.