

Issue Date: September 6, 2017

Call for Grant Notification: Healthcare-Related Charitable Support

The Alliance and Advocacy Relations team at Genentech, a member of Roche Group, invites the non-profit community to submit applications for grants subject to the terms below. This Call for Grants Notification (CGN) provides public notice of the availability of funds in a general topic area for activities for which recognized needs exist.

Purpose: As part of our mission and commitment to philanthropy, Genentech supports non-profit organizations **focusing on patient education, patient services and advocacy**. The purpose of this CGN is to support initiatives focused on the patient and caregiver community. Support requests must be healthcare-related and consistent with therapeutic or technological area(s) in which Genentech and/or Roche is active.

Notification: Genentech CGNs are made available through the online Genentech Funding Request System (gFRS) site (<http://funding.gene.com>). In addition, an email is distributed to registered gFRS users who have previously applied for healthcare-related charitable support.

Eligibility Criteria: Applicants must be U.S.-based and registered on the Genentech Funding Request System (gFRS). Each applicant's organization must be recognized by the IRS as a tax exempt, public charity under section 501(c)(3) of the Internal Revenue Code and must be located in the United States.

Geographical Scope: The programs and services **must be U.S.-based only**.

Submission Instructions for Executive Summary:

1. Applicants who meet the eligibility criteria and are interested in submitting a response to this CGN must first complete a brief **Executive Summary** through the following link:

<https://goo.gl/forms/rMtY841gQ8AMRVPi2>

Deadline for Executive Summary submission will be 9/22/2017 (11:59 Pacific Time).

Note: Do not submit your initial application through gFRS.

2. By **10/6/2017**, a Genentech Grant Manager will contact (i.e. by email) those applicants whose Executive Summaries were selected for further review.
3. Those applicants who receive notifications of potential interest may then submit full grant proposal applications online through gFRS. Further instructions will be provided in the email notification. Deadline to submit full grant proposal will be **10/20/2017 (11:59 Pacific Time)**.

Award Decision Date/Mechanism: Final approvals and denials for those who are selected to submit a full application in gFRS will be communicated via standard grant-submission means (i.e. email notifications) no later than **11/30/2017**. *There have been no pre-determined approvals.*

Applicants should not respond to this CGN unless they have read and understood the terms, purpose and requests identified below. Applicants are expected to identify and address issues that are aligned to this CGN.

This CGN will fund one project up to \$50,000. Please note that Genentech cannot be the sole sponsor for any given project.

**Topic and
Funding
Priorities****Addressing Unmet Needs in Hemophilia**

As part of our commitment to philanthropy, Genentech supports nonprofit organizations focusing on patient education, patient services and advocacy. The purpose of this CGN is to support initiatives focused on the patient and caregiver community. Support requests must be healthcare-related and consistent with therapeutic or technological area(s) in which Genentech and/or Roche is active. Types of programs and services considered as part of this CGN include, but are not limited to the following: Patient Services, Patient Outreach, Patient Education and Disease Education.

**Introduction
and
Background**

The Centers for Disease Control and Prevention estimates that there are approximately 20,000 people in the US living with hemophilia.¹ Hemophilia is a hereditary bleeding disorder, which is caused by an inherited deficiency of factor VIII (hemophilia A) or factor IX (hemophilia B).² While services exist for individuals and families impacted by hemophilia across the United States, several underserved populations exist. For example, minority populations and those not receiving coordinated care may be considered underserved. The inhibitor population, in particular, is an underserved population with notably different experiences than those without inhibitors.³ Despite the fact that one-third of people living with hemophilia A and three to five percent of hemophilia B develop inhibitors,³ this subpopulation remains understudied.³ Existing literature suggests families living with an inhibitor patient in the family have decreased HRQoL (Health-related quality of life) and experience more burden than those without inhibitors.⁴ Furthermore, people with inhibitors may experience unique challenges⁴, including isolation⁵, which may have an impact on quality of life for both the person diagnosed with hemophilia and their caregiver.⁵ Studies point to how "perceived support" can impact HRQoL.⁶

The future state of programming for underserved hemophilia populations, including inhibitor programming, should be considered alongside evolving trends in how individuals impacted by chronic diseases receive information and support services. People living with chronic diseases and their caregivers are increasingly seeking information from sources beyond their healthcare provider. Online communities, peer networks and web-based tools provide patients and their care partners with real-time information. Research shows that people living with chronic diseases and their caregivers may benefit from engagement in support platforms, social networks and online communities where individuals can exchange health information and disease experiences with their peers.⁷ Additionally, online interactive tools and learning can function as an alternative tool of support for individuals impacted by chronic conditions, helping individuals with the everyday stresses of their disease.⁸

**Call for Grants
Notice
Requirements
and Aim****Aim**

The aim of this CGN is to support proposals that focus on programs/services to address documented unmet needs in the patient community, including, but not limited to:

- Creation of easy to understand educational materials that provide accurate and balanced information about hemophilia with inhibitors
- Development of digital platforms and online technologies to raise awareness and understanding of issues related to hemophilia with inhibitors
- Creation of tools and resources for patients and caregivers that increase their ability to engage in discussions with their healthcare team

- Development of virtual and local programs that create community for and provide psychosocial support to people living with hemophilia with an inhibitor and their families

Call for Grants Notice Requirements

Proposals should define the unmet need being addressed in the project and utilize evidence from internal (e.g., surveys of constituents, qualitative data from front-line staff) and external (e.g., consensus reports, peer-reviewed journal articles) data sources to help establish a clear view on the unmet need.

Successful applications will include patient-focused solutions to documented unmet needs through a project that includes: an innovative program or service, well-defined process and outcome evaluation metrics, and a conceptual plan for expansion and sustainability.

Novel and non-traditional models of service delivery are encouraged. Applicants are also encouraged to utilize a collaborative approach to this effort and work with other organizations, though each application must be submitted individually by a single organization selected to represent the project for this CGN.

Additional Considerations: Grant requests must be submitted according to the deadlines provided above. The following uploads are required to submit your application: W-9 Form / W-8BEN form, promotional materials and/or event advertising (if applicable), meeting agenda (if applicable) and detailed / itemized program budget.

Genentech's Grant Decision-Making Policy: Please refer to the publicly available criteria, which can be found at <http://funding.gene.com>.

Terms and Conditions:

1. All grant applications received in response to this CGN will be reviewed in accordance with Genentech policies and policy guidelines.
2. This CGN does not commit Genentech to award a grant or to pay any costs incurred in the preparation of a response to this request.
3. Genentech reserves the right to approve or deny any or all applications received as a result of this request or to cancel, in part or in its entirety, this CGN.
4. For compliance reasons, and in fairness to all applicants, all communications about this CGN must come exclusively to Genentech's department of Alliance and Advocacy Relations.
5. Failure to follow instruction within this CGN may result in a denial.

Transparency: Genentech, at its sole discretion, has the right to disclose the details of funded healthcare related charitable support, including those that may be required by federal, state, and/or local laws and regulations. This disclosure may include, but shall not be limited to, details of the activity and the grant amount. The information may be disclosed to the public in a manner including, but not limited to, disclosure on the Genentech website.

References:

¹ Hemophilia. Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/hemophilia/data.html>. Published July 11, 2016. Accessed August 3, 2017.

² Mannucci PM, Tuddenham EG. The Hemophilias — From Royal Genes to Gene Therapy. *New England Journal of Medicine*. 2001;344(23):1773-1779. doi:10.1056/nejm200106073442307.

³ Zakarija A, Harris S, Rademaker AW, et al. Alloantibodies to factor VIII in haemophilia. *Haemophilia*. 2011;17(4):636-640. doi:10.1111/j.1365-2516.2010.02468.x.

⁴ Gringeri A, von Mackensen S, Auerswald G et al. Health status and health-related quality of life of children with haemophilia from six West European countries. *Haemophilia* 2004; 10(Suppl. 1): 26–33.

⁵ Dekoven M, Karkare S, Lee WC, et al. Impact of haemophilia with inhibitors on caregiver burden in the United States. *Haemophilia*. 2014;20(6):822-830. doi:10.1111/hae.12501.

⁶ Dekoven M, Wisniewski T, Petrilla A, et al. Health-related quality of life in haemophilia patients with inhibitors and their caregivers. *Haemophilia*. 2012;19(2):287-293. doi:10.1111/hae.12019.

⁷ Willis E. The making of expert patients: The role of online health communities in arthritis self-management. *Journal of Health Psychology*. 2013;19(12):1613-1625. doi:10.1177/1359105313496446.

⁸ Kostova Z, Caiata-Zufferey M, Schulz PJ. Can social support work virtually? Evaluation of rheumatoid arthritis patients' experiences with an interactive online tool. *Pain Research and Management*. 2015;20(4):199-209. doi:10.1155/2015/497512.