

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 and medical 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 in the Idiopathic Pulmonary Fibrosis space that are **focused 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/r4VIQyRXmgOpylsz1>
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 \$40,000. Please note that Genentech cannot be the sole sponsor for any given project.

**Topic and
Funding
Priorities****Idiopathic Pulmonary Fibrosis Education**

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**

Idiopathic pulmonary fibrosis (IPF) is a chronic lung disease of unknown origin which leads to a progressive decline in lung function¹ that often has a negative physical and emotional impact on a patient's quality of life.² Due to the nonspecific nature of its typical symptoms and limited knowledge about IPF, diagnosis is often considerably delayed, with over half of patients experiencing a delay of more than one year between initial presentation and confirmed diagnosis.³ Research suggests it is important that patients with IPF are diagnosed quickly and have access to care.⁴

Newly diagnosed patients have a need for disease specific information and education. However, after an often prolonged path to proper diagnosis, patients frequently report receiving inadequate information about both the disease and its prognosis.^{5,3} While the level of disease awareness varies widely among patients, a significant percentage of patients report feeling inadequately aware of or informed about IPF and would like to have a better understanding of the disease.²

The emotional and support needs of caregivers of IPF patients are also critical.² Caregivers can play a critical role in the life and care of an IPF patient.² However, they frequently report feeling inadequately prepared for the caregiving role and need to receive psychological support, help with strategies to manage daily life functions for the patient and more education and information on IPF.²

To fill that information gap, IPF patients/caregivers often turn to the Internet as a resource for health information.⁶ Patients are interested in general information about IPF, specific treatment options, updates on new research and therapies as well as practical information about lifestyle modifications that could help them manage their disease.²

However, research has shown and patient surveys have confirmed² that patient-directed online information on IPF could be further developed.⁶ This current limitation may present a significant barrier to patients playing an active role in their healthcare.⁶

In addition to seeking disease education, information and resources, patients often cite the need for increased psychological support² as they frequently experience uncertainty and fear as a result of the unpredictable course of IPF.⁵ Additionally, patients often report feelings of social isolation and a desire to connect with other patients.⁷ The opportunity to interact with other IPF patients can provide significant benefits including psychological support and practical disease management tips.³

Patient advocacy organizations play an important role supporting patients with IPF, providing educational information and emotional support as well as creating networks and communities of affected patients.⁴ Patients also seek information from their local institution and community organizations. Research suggests additional programs and services are needed to fully address the needs of this underserved population.³

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 IPF for patients and caregivers.
- Development of digital platforms and online technologies to raise patients' awareness and understanding of issues related to IPF.
- Creation of tools and resources to support patients' ability to engage in discussions with their healthcare team.
- Development of virtual and local programs that create community for and provide psychosocial support to patients and caregivers.

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:

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- ¹ Zolak JS, de Andrade JA. Idiopathic pulmonary fibrosis. *Immunol Allergy Clin North Am* 2012; 32: 473-485
- ² Russell A-M, Ripamonti E, Vancheri C. Qualitative European survey of patients with idiopathic pulmonary fibrosis: patients' perspectives of the disease and treatment. *BMC Pulmonary Medicine*. 2016;16(1). doi:10.1186/s12890-016-0171-y.
- ³ Schoenheit G, Becattelli I, Cohen A. Living with idiopathic pulmonary fibrosis: an in-depth qualitative survey of European patients. *Chronic Respiratory Diseases*. 2011; 8(4):225-231. Doi:10.1177/1479972311416382.
- ⁴ Bonella F, Wijssenbeek M, Molina-Molina M, et al. European IPF Patient Charter: unmet needs and a call to action for healthcare policymakers. *European Respiratory Journal*. 2015;47(2):597-606. doi:10.1183/13993003.01204-2015.
- ⁵ Wuyts WA, Peccatori FA, Russell A-M. Patient-centred management in idiopathic pulmonary fibrosis: similar themes in three communication models. *European Respiratory Review*. 2014;23(132):231-238. doi:10.1183/09059180.00001614.
- ⁶ Fisher JH, O'Connor D, Flexman AM, Shapera S, Ryerson CJ. Accuracy and Reliability of Internet Resources for Information on Idiopathic Pulmonary Fibrosis. *American Journal of Respiratory and Critical Care Medicine*. 2016;194(2):218-225. doi:10.1164/rccm.201512-2393oc.
- ⁷ Duck A, Spencer LG, Bailey S, Leonard C, Ormes J, Caress A-L. Perceptions, experiences and needs of patients with idiopathic pulmonary fibrosis. *Journal of Advanced Nursing*. 2014;71(5):1055-1065. doi:10.1111/jan.12587.