



Request for Proposals

Impact Awards:

Building on Successful Outreach and Education Programs to Improve Access to Genetic Services and Support

Due:

March 14, 2014
8:00 pm EST

Submit To:

Sharon Romelczyk, MPA
Program Manager
sromelczyk@geneticalliance.org

or

Genetic Alliance
ATTN: Sharon Romelczyk, Program Manager
Re: Genetics Education and Outreach Program Award
4301 Connecticut Ave NW
Suite 404
Washington, DC 20008

Request for Proposals

Purpose: To expand the reach of existing collaborative projects that demonstrate the ability to improve access to genetic services and support. Funding from this award cannot be used for developing new projects.

Qualification: Eligible applicants include state governments, Native American tribal organizations (other than Federally recognized tribal governments), nonprofits having a 501(c)(3) status with the IRS, and institutions of higher education. **All applicants must be located in and serve the United States and/or US territories.**

Timeline:

Request for proposals released:	January 17, 2014
Informational webinar:	January 23, 2014
Letter of intent deadline for submissions	February 15, 2014
Proposals due	March 14, 2014
Applicants notified of funding decisions	April 2, 2014
Funding period begins	May 1, 2014

Information Regarding this Award:

This Request for Proposals as well as Frequently Asked Questions, Budget Templates, and other supporting documents are available at www.geneticalliance.org/ImpactAwards

Submission of Questions:

Inquiries regarding specifications should be submitted via email to Sharon Romelczyk at sromelczyk@geneticalliance.org.

An informational webinar will take place on Thursday, January 23, 2014 from 12:00-1:00 pm EST to address general questions regarding this funding opportunity. If you have a question to submit to be addressed during this webinar, please send those in advance to sromelczyk@geneticalliance.org. There will be an opportunity to ask questions during this forum. All questions and answers from this webinar as well as the webinar recording will be made available.

Link to participate in informational webinar:

<https://attendee.gotowebinar.com/register/655693015523898113>

Background

Individuals with genetic conditions and their families often face barriers that prevent them from accessing genetic services (such as genetic testing, counseling, and screening) and support. Barriers may include knowledge gaps in the importance of screening, where to access genetic services, and the types of providers they should be seeing for their specific health needs. Other factors that impact access and care can result from systemic issues, such as not having adequate insurance coverage for necessary care. Peer support, family advocacy, and

disease-specific organizations are available to offer social and emotional support, assistance navigating the complex health system, and education on available services; however, individuals are not always referred to or connected with these available support services.

Resources and education about what services and support are available can help empower individuals to be in control of their own health and care. Several programs exist with the goal of improving access to care for this population, however many focus on improving systemic barriers. Many successful education and outreach programs directed at individuals affected or at-risk for genetic conditions and their families have shown an impact on access to care (increase in knowledge about and utilization of genetic services, screening, etc.). Unfortunately, oftentimes these outreach and education programs are funded as short-term pilot projects that are not sustained after funding ends.

In June 2012 Genetic Alliance was awarded a grant to create a National Genetics Education and Consumer Network (NGECN) with the goal of empowering consumers (individuals with or at risk for genetic conditions and their families), as well as the general public to better understand and access genetics services. Through partnerships and accessible tools, NGECN aims to increase access to and knowledge about genetics services, as well as work to improve the quality of those services.

The National Genetics Education and Consumer Network (NGECN) is a three-year program focused on consumer education and engagement in conjunction with efforts of the American College of Medical Genetics' [National Coordinating Center for the Regional Genetic Service Collaboratives](#) (NCC). The NCC provides support and resources to the seven [Regional Genetics Collaboratives](#) (RCs), programs funded to enhance all aspects of genetic services. The RCs aim to improve the lives of people with special healthcare needs and their families through coordinated, family-centered, community-based care. With and for consumers, the RCs are instrumental in improving health through newborn screening, medical home and transition, care coordination, and other initiatives.

NGECN is funded by the Health Resources and Services Administration (HRSA), Genetic Services Branch of the Maternal and Child Health Bureau, Cooperative Agreement no. U22MC04100, National Coordinating Center for the Regional Genetic Services Collaboratives.

Grant Focus

Impact Award recipients will expand upon existing genetics-related outreach and education programs to increase their reach and demonstrate an increased impact on improving access to screening, services, support, as well as consumer empowerment. Award recipients are required to demonstrate a minimum of ONE of the following expansion methods:

- Expand upon existing activities to target new disease populations
- Expand the capacity of an existing project to reach a new geographical area (state or regional)
- Build upon existing efforts using a novel or targeted method of outreach

Programs should look to create novel partnerships and strengthen existing partnerships that will help them expand their activities, reach larger numbers of consumers, and/or expand to reach a new population (i.e. new condition or disease). The goal of this project is to establish sustainability through buy-in from outside partners of a proven approach to outreach and education.

Awards will include costs for developing and implementing the expansion activities. Programs must incorporate evaluation metrics to report impact of the program. Impact Award recipients will be required to write a final report, including a model project description, and any data to support the impact of the project. This should contain a timeline, outcomes, and concrete details of project maintenance, such as staff time and budget specifics. Project descriptions will be compiled and published to encourage future expansion and replication of genetics-related outreach and education initiatives.

Available Funding

Organizations may apply for up to \$25,000 as a base award. Funding levels will be determined by the breadth of activities proposed. A total of \$175,000 will be distributed as part of this award process.

How to Apply

Applicants are encouraged to submit a Letter of Intent (LOI) via email (LOIs sent by post are also accepted). The deadline for receipt of LOIs is 8:00 p.m. EST on February 15, 2014.

A reference document, the *Guide to Successful Outreach and Education Programs*, will be shared with all organizations that submit a Letter of Intent. Genetic Alliance partnered with the Regional Genetics Collaboratives to produce this guide highlighting existing genetics-related projects aimed at educating and/or empowering individuals with or at risk for genetic conditions and their families. The guide provides strategies and lessons learned from existing programs on planning, developing, implementing, and evaluating outreach and education efforts. This document is intended to suggest potential ways to expand upon and strengthen your proposed efforts.

Full proposals must include the following:

- Proposal narrative (including work plan and timeline) (8 page limit)
- Budget with justification and description of in kind funding (Because of the size of the award, **proposals should not include indirect costs**)
- Three letters of support
- Biographical sketches of key personnel directly involved in this project

Narratives must:

- Clearly define the population to be served.
- Include a complete narrative description of the proposed program, including goals, objectives, activities, evaluation, timelines, and anticipated outcomes.

- Describe any potential limitations to implementation, such as being subject to the jurisdiction of some state or federal agency or other regulations.

The deadline for receipt of full proposals is 8:00 p.m. EST on March 14, 2014. Submissions can be made via email or post.

Evaluation Criteria

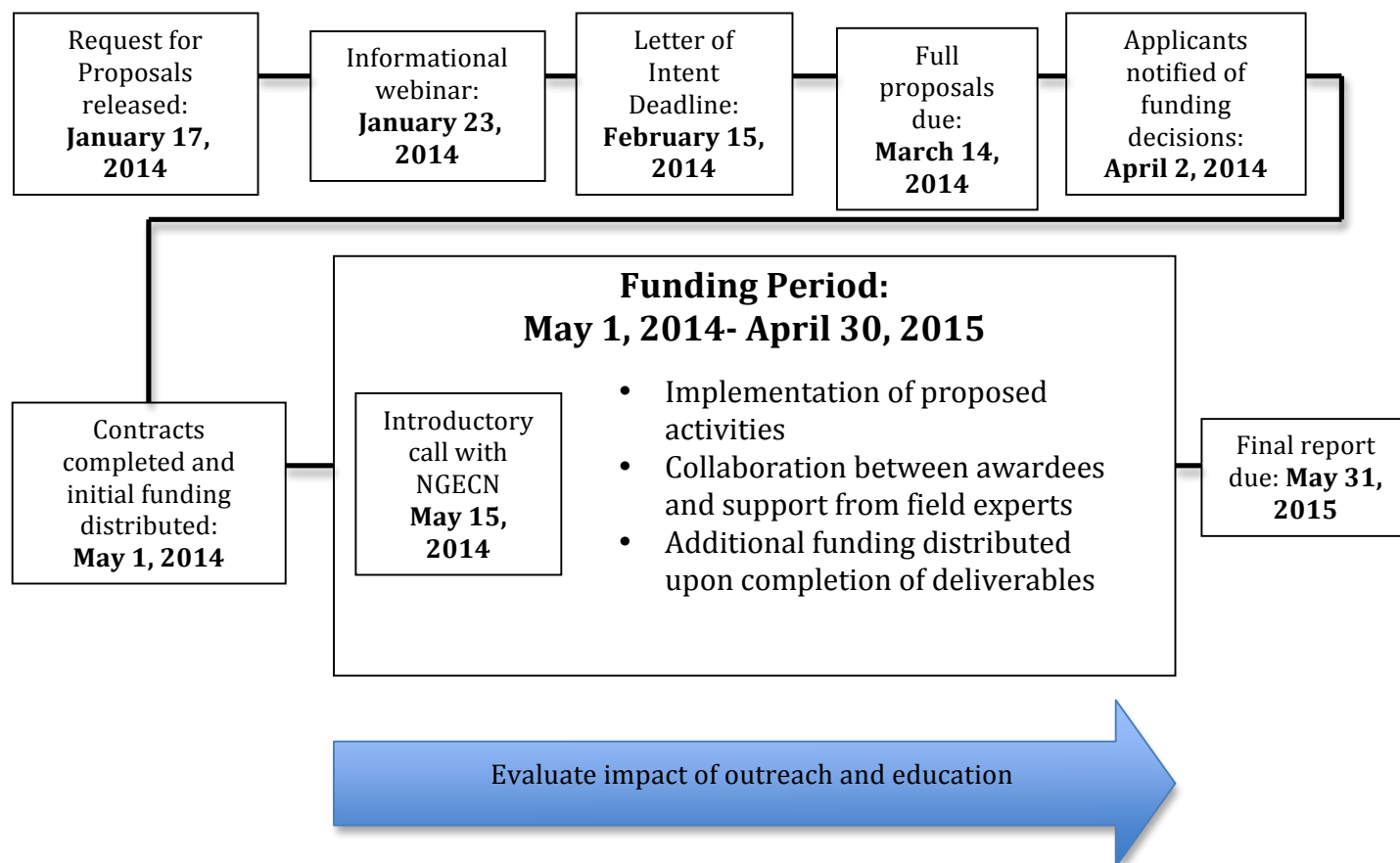
Applications will be reviewed by the Consumer Advisory Group of the National Genetics Education and Consumer Network (NGECN).

Proposals will be assessed based on the following criteria:

- Adherence to RFP guidelines (Yes/No)
- Adherence to RFP timeline and budget (this can be supplemented by other funding sources) (Yes/No)
- Clear description of the goals, objectives, activities, and anticipated outcomes (10 points)
- Builds upon a project that has been shown to significantly improve access to genetic services and support (20 points)
- Significant expansion of an existing project (size of population, additional diseases, geographically) (30 points)
- Increased support or access in a population with demonstrated need (10 points)
- Demonstrated capacity to implement the proposed initiative (staff time and expertise, experience working with this population, ability to measure success, and description of plans for implementation and any potential limitations) (20 points)
- Strong collaboration with existing community and state-based organizations (e.g. [Regional Genetics Collaboratives](#)) (10 points)

Genetic Alliance will make the final award decisions. In making these decisions, Genetic Alliance reserves the right to conduct discussions with proposers, to accept revisions of proposals, to negotiate price changes, or to decide not to fund any programs if it is determined that an insufficient number of quality proposals have been submitted. During this discussion period, Genetic Alliance will not disclose any information regarding proposal submittals. Genetic Alliance will take into consideration the application scores as determined by the composite score of the reviewers; the geographic distribution of the potential awardees; the diversity of populations served by potential awardees; and the methods of integration proposed by potential awardees.

Timeline for Impact Awards



About Genetic Alliance

Genetic Alliance is a nonprofit health advocacy organization that transforms health by engaging individuals, families, and communities. We bring together diverse stakeholders to create novel partnerships in advocacy. We promote individualized decision making through increased access to information. We integrate individual, family, and community perspectives to improve health systems and services.

Inquiries and Additional Information:

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