



Request for Proposals

2012 Baby's First Test Challenge Awards

Due:

November 7, 2011
6:00 pm EST

Deliver To:

Natasha Bonhomme
Vice President of Strategic Development
Genetic Alliance

Preferred method: Email as attachment to info@babysfirsttest.org

Secondary method: Mail ATTN Natasha Bonhomme
Genetic Alliance

Re: BabysFirstTest.org Challenge Awards
4301 Connecticut Ave NW
Suite 404
Washington, DC 20008

2012 Baby's First Test Challenge Awards Request for Proposals

Purpose: To expand or create new outreach, engagement, or educational programs for newborn screening with attention to sustainability and integration of Baby's First Test (www.BabysFirstTest.org).

Target Populations: Expectant parents, parents of a child recently diagnosed with a condition included in state newborn screening panels, members of the public, healthcare providers, and/or researchers.

Timeline

Request for proposals released: October 6, 2011

Question period: October 6 – October 20, 2011

Informational Webinar: October 21, 2011, 12:00-1:00 pm EST

Questions and answers released: October 25, 2011

Proposals due: November 7, 2011, 6:00 PM EST

Applicants notified of funding decisions: December 1, 2011

Funding period: January 1 – August 31, 2012

Submission of Questions

Inquiries regarding specifications shall be submitted in writing via email to Natasha Bonhomme, Vice President of Strategic Development/Project Director. Please allow two business days for a response. At the close of the question period, a list of questions and answers will be posted on www.BabysFirstTest.org. Email questions to info@babysfirsttest.org.

Background

Newborn screening in the United States reaches more than four million babies every year and identifies thousands of newborns with genetic, metabolic, or functional disorders. Early diagnosis allows timely intervention for these newborns, leading to a significant reduction in morbidity, mortality, and associated disabilities. As newborns are screened for an increasing number of conditions, there is a growing need for centralized, easily accessible, and accurate information for newborn screening stakeholders, including parents, members of the public, healthcare providers, and researchers.

In September 2009, Genetic Alliance and partners were awarded a cooperative agreement from the Health Resources and Services Administration to develop the nation's first clearinghouse of newborn screening information, as mandated in the [Newborn Screening Saves Lives Act of 2008](#). Through this mandate, Baby's First Test (www.BabysFirstTest.org) was created as a one-stop shop for newborn screening information that directs users to current information, materials, resources, research, and data on newborn screening education, family support, and services. In addition to increasing awareness, knowledge, and understanding of newborn screening as a process and system, over the past year Baby's First Test has connected key stakeholders to state and regional resources that are highly valuable, but historically difficult to find or access due to the high costs of dissemination and outreach. The recently redesigned Baby's First Test was

launched at the beginning of September 2011, providing both a streamlined and dynamic resource for the newborn screening community.

Our first set of Challenge Awardees produced inventive and engaging projects that helped to educate and increase awareness about newborn screening and Baby's First Test. Among the many activities and items produced by the Challenge Awardees were the utilization of social media to increase awareness of newborn screening, assessment of online health information-seeking behaviors, production of a 2.5-minute video vignette in English and Spanish depicting an obstetrician discussing newborn screening with her patient, and the facilitation of a childbirth educator meeting that included doulas, nurse-midwives, and childbirth educators. We are excited to see what this next round of Challenge Awards brings!

Baby's First Test is supported through cooperative agreement U36MC16509 from the Department of Health and Human Services, Health Resources and Services Administration, Genetic Services Branch of the Maternal and Child Health Bureau.

Purpose: Baby's First Test 2012 Challenge Awards

The newborn screening community is one of great innovation. In light of this tradition, Baby's First Test seeks to engage and inspire the community through the Challenge Awards. Baby's First Test is a one-stop shop for newborn screening information, so all stakeholders are integral to the development of the resource as a website, tool, and an initiative.

Genetic Alliance will fund submissions that propose innovative solutions to a number of challenges, including but not limited to the following examples:

- Integrating educational multimedia into www.BabysFirstTest.org, such as topics relating to experiences with newborn screening and instructional videos for professionals, especially those around false positive experiences and bloodspot retention.
- Strengthening the cultural competency of www.BabysFirstTest.org.
- Increasing the accessibility of the website to non-English speakers, as well as for hearing and visually impaired audiences.
- Integrating health information technology and newborn screening.
- Engaging networks of consumers and parents in testing of www.BabysFirstTest.org, both virtual and physical.
- Conducting outreach or usability testing on behalf of Baby's First Test, particularly to underserved populations or regions.
- Incorporating newborn screening information and Baby's First Test in key online resources for expectant or recent parents.
- Adapting resources with proven value to the newborn screening community for inclusion in Baby's First Test.

Projects can focus on the development of materials for conditions added to the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children's Recommended Uniform Screening Panel (SACHDNC RUSP) within the past two years. Those conditions are Severe Combined Immunodeficiency (SCID) and Critical Congenital Cyanotic Heart Disease (CCCHD). Other condition-specific materials will not be considered for the NBSC Challenge

Awards. We encourage the development of materials that are at an eighth grade literacy level or lower to promote accessibility for the public. Resources in languages other than English are also encouraged.

Genetic Alliance staff will provide technical assistance to Award recipients as needed for the incorporation of tools into www.BabysFirstTest.org.

Eligibility

Genetic Alliance will consider proposals submitted from nonprofit organizations, public research institutions, and private-sector companies. Proposals from individuals will not be considered.

Genetic Alliance will work directly with Challenge Award recipients, not through third party organizations. Award recipients must be located in and serving the United States and/or US territories.

All educational information developed or adapted through these awards must be applicable outside states lines, meaning regionally or nationally.

Organizations may not submit proposals for projects that already have a dedicated funding source. However, proposals to translate or update outdated resources funded by another project are acceptable.

If you have questions about your eligibility, please contact Natasha Bonhomme, Project Director, at info@babysfirsttest.org.

Available Funding

Baby's First Test has dedicated funding for January 2012 – August 2012 to distribute Challenge Awards. Organizations may apply for up to \$20,000. If there is a surplus of funds, there may be opportunity to apply for a supplement.

How to Apply

Complete proposals must include the following:

- Identification of the primary contact for the project
- Proposal narrative (8 page limit, 12 pt Times New Roman font, one inch margins, single spaced)
- Work plan and timeline (not included in page limit)
- Budget with justification (not included in page limit)
- Resumes of key personnel directly involved in this project (not included in page limit)
- A statement of conflict of interest (not included in page limit)
- If applicable, letters of support from partner organization (not included in page limit)

Narratives must include (all required):

- A brief description of the organization's mission,
- A complete narrative description of the proposed project, including goals, target audience, activities, timelines, anticipated outcomes, and evaluation plan, and,

- A description of the technical assistance needed from Genetic Alliance to complete the project in the proposed timeline.

Budgets must include:

- The total project cost, as well as detailed “line item” costs for components/phases of the project
- All hourly rates and fees, charges, costs, and anticipated reimbursable costs

A question and answer webinar will be held on October 21, 2011, 12:00-1:00 pm EST. Visit <http://www.geneticalliance.org/webinars> to register.

The deadline for receipt of full proposals is 6:00 p.m. EST on November 7, 2011. Genetic Alliance prefers that proposals be submitted via email to info@babysfirsttest.org.

Evaluation Criteria

A team of external reviewers and internal reviewers (Genetic Alliance and HRSA) will be appointed to review each application. Reviewers will evaluate the narrative content of each application based on the scoring system outlined below. External reviewers are selected based on their knowledge, expertise, and experience in newborn screening systems. External reviewers that submit a proposal will not score their own application. Genetic Alliance and HRSA project staff will make the final award decisions. In making these decisions, the Genetic Alliance and HRSA project staff will take into consideration the application scores as determined by the composite score of the reviewers; the breakthrough innovation potential of applications; geographic distribution of the potential awardees; and the distribution of potential awardees across identified topics.

Scoring Criteria	Points
Proposal Clarity	
How clearly does the applicant describe the goals, objectives, activities, and anticipated outcomes?	5
Does the applicant demonstrate adequate staff and capacity to successfully complete the project?	5
Impact	
How clearly does the applicant define the problem or challenge?	10
How well does the applicant describe how the project will address the problem or challenge?	20
How suitable is the evaluation plan to assess the impact of the project?	20
Engagement	
How well does the project promote community investment in newborn screening and the Clearinghouse?	20
Does the applicant demonstrate the experience and ability to successfully work with the target community?	10
Innovation	
How novel is the project; does it avoid duplication of current efforts in the newborn	10

screening community?	
Does the applicant demonstrate a creative use of funding to spur innovation in the community?	20
Sustainability	
How well does the project utilize existing programs, systems, networks, or resources?	10
How well will the project continue to engage the community around newborn screening and the Clearinghouse after the funding period ends?	20
Total	150

Genetic Alliance reserves the right to conduct discussions with applicants, to accept revisions of proposals, to negotiate price changes, or to negotiate separately with any source whatsoever if it is determined by Genetic Alliance that an insufficient number of quality proposals have been submitted. During this discussion period, Genetic Alliance will not disclose any information regarding proposal submittals.

Inquiries and Additional Information:

Natasha Bonhomme, Vice President of Strategic Development
Genetic Alliance
4301 Connecticut Ave., N.W. Suite 404
Washington, DC 20008-2369

Phone: 202.966.5557 x211
Fax: 202.966.8553
Email: info@babysfirsttest.org
Website: www.BabysFirstTest.org