



Request for Applications

Consumer Task Force on Newborn Screening

Due:

February 10, 2016
6:00 pm EDT

Deliver To:

Natasha F. Bonhomme
Director, Baby's First Test

Preferred method: Email as attachment to Natasha@BabysFirstTest.org

Secondary method: Mail
Genetic Alliance

ATTN Natasha Bonhomme

Re: Consumer Task Force on Newborn Screening/ Baby's First Test
4301 Connecticut Ave NW
Suite 404
Washington, DC 20008

2016 Consumer Task Force on Newborn Screening Request for Applications

Summary: The Consumer Task Force on Newborn Screening was created to engage relevant stakeholders with an interest in newborn screening policies, activities, and current events. The two components of this program are training and project development. Members of the Task Force will be trained on issues relevant to newborn screening and will create projects targeting groups who typically are under-informed about the importance of newborn screening. A key tool for these projects will be www.BabysFirstTest.org. After serving on the Task Force, members will be equipped with the skills and knowledge to continue work on newborn screening programs or other maternal and child health-related issues. No previous experience is necessary, only a desire to learn about and to make a positive impact in newborn screening and maternal and child health. Upon completion of Task Force activities, members will receive a certificate acknowledging the training they received.

Target Applicants:

Consumer Task Force members will have a wide variety of experiences with newborn screening. In particular we are seeking members who demonstrate some of the following:

- Have an interest in newborn screening and/or public health
- Have a child/family member who was identified with a condition by newborn screening
- Have a child/family member who has a condition that could have been identified by newborn screening
- Have a child/family member who had an uneventful (typical) newborn screen
- Are currently pregnant or are planning to become pregnant
- Have a child/family member who had a screen positive result, but did not end up having that condition (false positive)
- Represent typically underserved populations
- Have a desire to create broad change or increase understanding of newborn screening
- Currently educate parents and/or the public about health issues

Timeline

Request for applications released: January 12, 2016

Last day to submit questions: January 22, 2016

Q&A posted online: January 25, 2016

Applications due: February 10, 2016 by 6:00 PM ET

Applicants notified of acceptance decision: February 17, 2016

Signing of Contracts completed by: February 24, 2016

Official dates of Task Force Activity: March 1, 2016 - December 31, 2016

Announcement of Consumer Task Force: March 1, 2016

First Consumer Task Force Introductory Call: March 7, 2016

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.

Since its launch in September 2011, Baby's First Test (www.BabysFirstTest.org) has provided up-to-date information, materials, resources, research, and data on newborn screening education, family support, and services to over 1 million parents, healthcare providers, and other stakeholders. For years, members of the public have worked to shape newborn screening policy and inform decisions. With the current technological advances that are quickly changing the face of newborn screening, it is important to continue engaging parents and the general public so that their voices can be heard.

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.

Participation Guidelines for the Consumer Task Force on Newborn Screening

People who are most likely to need this information are in the best position to address gaps in dissemination. These stakeholders, such as parents, grandparents and health professionals, have a unique perspective on what steps should be taken to ensure that all members of our community have access to the same high quality information.

Participation in the Consumer Task Force will have three Phases: Introduction and Training, Project Planning, and Project Implementation. In the Introduction and Training Phase we will provide the context for current newborn screening practices and policies to give participants a better idea of why programs and activities are structured the way they are. Topics will include newborn screening from the federal and state perspectives, advisory committees that make decisions, and different avenues of involvement. Phase one will also cover useful tools for engagement, such as social media training, and hot topics in the newborn screening community.

In the Project Planning Phase, Task Force members will identify a specific audience that they would like to target through a pilot outreach campaign and draft a proposal for that outreach. The audience can be specific, such as yoga moms, or general, such as first time moms; the only requirement is that the Task Force member is passionate about that community and has a desire to increase that group's awareness of newborn screening. Task Force members will have an opportunity to discuss their projects with the program's Advisory Partners. These partners have served on a previous task force or have other relevant knowledge of newborn screening from a parent perspective. Advisory Partners will act as a sounding board and provide guidance on project proposals – they might help to ensure the project scope fits within available resources and timeframe or identify roadblocks that should be addressed before the project begins. Funding will be available to help offset the cost of the project, please see the "Compensation" section below.

The Project Implementation Phase will largely depend on the individual project proposals, which will reflect the best avenues for each Task Force member to reach their intended audience.

Examples of potential projects are as follows:

- Create campaigns for a particular community or online audience
- Attend meetings and prepare a poster or talk for presentation at a meeting
- Advocate for educational advancements in newborn screening at the state or federal level

Towards the end of the commitment, Task Force members will share their projects with each other to distill lessons learned and brainstorm ways other targeted communities can adapt the projects to fit their needs.

Genetic Alliance staff will provide technical assistance to Consumer Task Force members as needed with particular attention to the incorporation of products into <http://www.BabysFirstTest.org>.

Consumer Task Force Expectations (approximately three hours per month total)

- Participate in monthly phone calls, to be coordinated with Task Force members' schedules (lasting approximately 60 minutes)
- Engage a target audience of interest with a project aimed to increase their knowledge of newborn screening in general, and Baby's First Test in particular
- Participate in a review of materials when requested (totaling three hours throughout the program)
- Participate in open and clear communication with Genetic Alliance/Baby's First Test staff
- Participate in periodic evaluation of the Consumer Task Force with an effort to continually improve the program (four evaluations taking approximately 15 minutes to complete)
- Write a summary final report of the engagement project with lessons learned and ideas for continuation of the project

Eligibility

- Genetic Alliance will consider applications submitted from all individuals who have an interest in newborn screening. Applicants can be part of an organization or have no affiliations.
- Task Force members must be located in and serving the United States and/or U.S. territories.
- 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 but are not guaranteed to be funded.
- It is required that all educational materials produced as part of this project will be included on BabysFirstTest.org either through direct permission, co-ownership or Creative Commons license depending on the development process.
- If you have questions about your eligibility, please contact Natasha Bonhomme, Director, at Natasha@BabysFirstTest.org.

Compensation

Funding of \$1500 per member has been allocated to compensate members for their time on the Consumer Task Force. These funds can either be used as a stipend for time spent by members of the Task Force or to complete the project that the member is working on. Additionally, there are funds set aside to assist in copying and disseminating any materials that are created by the Consumer Task Force as part of their targeted stakeholder project.

The funding will be distributed on the following schedule:

- 25% (\$375) to be paid at completion of training
- 50% (\$750) to be paid once a project proposal has been submitted and discussed
- 25% (\$375) to be paid when project is complete and wrap-up report and evaluation have been submitted

How to Apply

Complete applications must include the following:

- Contact information for the applicant
- A resume highlighting past work experience and skills
- A statement of interest on the topic of newborn screening (1 page)
- Identification of at least one population that you have a particular interest in and feel could be better served with targeted information about newborn screening
- A personal letter of support from someone aware of your interests (optional)

The deadline for receipt of full proposals is 6:00 p.m. EDT on February 10, 2016. Genetic Alliance prefers that proposals be submitted via email to Natasha@BabysFirstTest.org. Applications should be no longer than 6 pages excluding letters of support.

Evaluation Criteria

A team of reviewer (internal and external) will assess the applications. 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, community engagement, and/or public health communications. Genetic Alliance and HRSA project staff will make the final award decisions. In making these decisions, Genetic Alliance and HRSA project staff will take into consideration the application scores as determined by the composite score; the breakthrough innovation potential of applications; geographic distribution of the potential projects; and the distribution of potential projects across identified topics.

Scoring Criteria	Points
Interest in Newborn Screening	
Has the applicant demonstrated a commitment to newborn screening and maternal and child health issues?	20
Diversity of Experiences	
Does the applicant have an interest or relationship with a typically underrepresented stakeholder?	20
Background Experience	

Does the person have appropriate background skills to successfully complete a project?	20
Does the applicant demonstrate the experience and ability to successfully work with the target community?	20
Innovation	
Is the applicant interested in increasing awareness of newborn screening in a novel way?	20
Total	100

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

Inquiries and Additional Information:

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