

Request for Proposals

WEBSITE DEVELOPMENT AND IMPLEMENTATION SERVICES
BabysFirstTest.org

Due:

December 17, 2010
6:00 pm EDT

Deliver To:

Natasha Bonhomme
Vice President of Strategic Development
Genetic Alliance
Preferred method: Email as attachment to nbonhomme@geneticalliance.org

Secondary method: Mail ATTN Natasha Bonhomme
Genetic Alliance
Re: BabysFirstTest.org Website Development
4301 Connecticut Ave NW
Suite 404
Washington, DC 20008

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I. OVERVIEW

A. Introduction

For more than 40 years, almost every infant born in the United States has been screened for an increasing number of genetic and heritable conditions at birth. Each condition included in these newborn screening (NBS) programs has an available, efficacious treatment that can significantly improve a child's health outcomes if his/her condition is identified early. Parents often are unaware of the number and types of screening that their children receive or the fact that NBS programs and policies vary from state to state. Issues in NBS are increasingly being discussed in the popular media, and members of the public and press are finding it difficult to locate quality, comprehensive information to answer questions prompted by the media coverage. Furthermore, the rapid expansion of NBS is outpacing efforts in public education and policy development. A central resource that provides quality information in an accessible and meaningful way to help parents and family members of newborns, health professionals, industry representatives, and the public navigate the newborn screening system is critically needed.

The US Congress passed the *Newborn Screening Saves Lives Act* in April 2008. The bill called for the establishment of an online clearinghouse of NBS information. In September 2009, Genetic Alliance and partners were awarded the cooperative agreement to establish the nation's first Newborn Screening Clearinghouse (NBSC), connecting millions of parents and healthcare providers with resources and information regarding the more than 4 million newborns screened annually. The NBSC will increase awareness and knowledge of newborn screening and improve the informed decision-making capacity of NBS stakeholders. It will also connect 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. To achieve these goals, Genetic Alliance must develop an online clearinghouse to serve as a one-stop-shop for newborn screening resources for all stakeholders.

Genetic Alliance is seeking services from a qualified and experienced web development firm to complete website development and implementation of the Clearinghouse. Genetic Alliance established a beta version of the Clearinghouse in the first year of the project (NBSClearinghouse.org). The project will involve utilizing current content on the existing beta site but will center upon the development of a completely new site and implementation of a more sophisticated information architecture that will involve the addition of content, information, and functionalities.

Genetic Alliance is looking to build a streamlined and customizable website user experience focusing on the populations outlined in the 2008 *Newborn Screening Saves Lives Act* legislation (expectant parents, parents of a child recently diagnosed with a condition included in state newborn screening panels, members of the public, healthcare providers, and researchers). Information provided to each user type is based upon Genetic Alliance's analysis of each user population's needs, and is included in Appendix A of the RFP. Genetic Alliance is interested in a dynamic, innovative design and architecture that engages the visitors, provides easy access to the information sought after, and enhances

individual knowledge and awareness of key aspects of the newborn screening process and system.

B. Submittal Deadline

To be considered, a PDF of the original proposal must be received by Genetic Alliance via email to nbonhomme@geneticalliance.org by 6:00 pm EDT on December 17, 2010. If mailing the proposal, (1) original and six (6) copies of the proposal must be received by Genetic Alliance, ATTN Natasha Bonhomme, at 4301 Connecticut Ave NW, Suite 404, Washington, DC 20008 by 6:00 pm EDT on December 17, 2010. Genetic Alliance reserves the right to accept or reject any or all proposals received or any parts thereof, or to negotiate separately with any source whatsoever if no acceptable proposals are submitted in order to best serve the interests of Genetic Alliance. The RFP is made for information and planning purposes only and does not obligate or bind Genetic Alliance contractually to accept any proposals submitted. The final award, if any, is contingent upon the successful negotiation of a separate written contract agreed to by the parties.

During the evaluation process, Genetic Alliance reserves the right, where it may serve Genetic Alliance's best interest, to request additional information or clarification from proposers, or to allow corrections of error or omissions. Proposals deemed incapable of meeting the scope and needs of the RFP in a satisfactory manner may be removed from further consideration.

C. Evaluation Schedule

Event	Date and Time
Request for Proposal Issued and Advertised	November 12, 2010*
Question Period Ends	December 10, 2010*
Proposals Due	December 17, 2010 6:00 pm EDT
Evaluation Period	December 18, 2010 – January 7, 2011
Anticipated Contract Award	January 10, 2011*
	**The noted dates and times are tentative and subject to change. For the date of contract award, the date provided is the latest date possible. Genetic Alliance reserves the right to notify a firm of its proposal's acceptance, as well as notify a firm of its proposal's rejection, prior to this date.*

II. SUBMISSION OF PROPOSALS

A. Mandatory

The following are mandatory for a proposal to be considered:

- Proposals must be complete without omissions.
- A signed signature page is a required part of the proposal.
- If proposals are mailed, they must be hand-delivered, mailed via USPS, or carrier or courier shipped.
- Completion of Appendix C, the "Cost Schedule," included in this RFP is required.
- Proposals must be emailed or received by Genetic Alliance no later than the date and time set forth for the closing of the RFP.

B. Incomplete Proposals

In order to be considered for evaluation, proposals submitted in response to this RFP must meet all required specifications. Proposals that are incomplete or unclear may be rejected, not evaluated, or returned with incomplete actions specified for response to be considered. Failure to take action in the time allotted will result in the proposal being rejected or not evaluated.

C. Submission of Questions

Questions and inquiries regarding specifications shall be submitted in writing via email to Natasha Bonhomme, Vice President of Strategic Development. At the close of the question period, all firms that have notified Genetic Alliance of their intent to submit a proposal will be provided the list of questions received by Genetic Alliance that were submitted during the question period (with firm name omitted) with their associated answers, to ensure all interested firms have equal access to information regarding the RFP. Email questions to Natasha Bonhomme at nbonhomme@geneticalliance.org

D. Proprietary Information

All materials and communication related to this RFP are to be kept confidential.

III. SCOPE OF WORK

A. Clearinghouse Background Overview

The US Congress passed the *Newborn Screening Saves Lives Act* in April 2008 as a bill to expand support, research, and education opportunities for newborn screening programs. The bill called for the establishment of an online clearinghouse of NBS information. In September 2009, Genetic Alliance and partners were awarded the cooperative agreement to establish the nation's first Newborn Screening Clearinghouse (NBSC), connecting millions of parents and healthcare providers with resources and information relevant to more than 4 million newborns screened annually. The NBSC will increase awareness and knowledge of newborn screening and improve the informed decision-making capacity of NBS stakeholders. To achieve this goal, Genetic Alliance must develop a Clearinghouse website to serve as a one-stop-shop for newborn screening resources for all stakeholders.

B. Legislative Requirements

The *Newborn Screening Saves Lives Act of 2008* requires that the Clearinghouse provide, at a minimum:

- Links to Government-sponsored, non-profit, and other Internet websites of laboratories that have demonstrated expertise in NBS that supply research-based information on NBS tests currently available throughout the United States
- Information about newborn conditions and screening services available in each State, including information about supplemental screening that is available but not required, in the State where the infant is born
- Current research on both treatable and not-yet treatable conditions for which newborn screening tests are available
- The availability of Federal funding for newborn and child screening for heritable disorders

The audiences that the Clearinghouse must address include expectant parents, parents of a child recently diagnosed with a condition included in state newborn screening panels, healthcare providers, members of the public, and researchers. To learn more, please visit the *Newborn Screening Saves Lives Act* legislative language currently available on the following Health Resources and Services Administration webpage: http://www.hrsa.gov/heritabledisorderscommittee/governance/newbornscreeningsavesliv es.htm

C. Progress to Date

Genetic Alliance established a beta website (www.nbsclearinghouse.org) of the Clearinghouse in the first year of the project to serve as a launching point for gathering stakeholder feedback on what should be included in the Clearinghouse. Since the new website will replace the beta site, no consideration must be made for shared platform or interoperability between the two websites, though there are significant requirements (as outlined in Appendix B) for interoperability with Genetic Alliance's backend database. We received input from the project Steering Committee, National Advisory Committee, and the Materials Working Group. The Materials Working Group was established to provide input on the organization and content of the educational materials included on the website, and they are currently working toward establishing policies and procedures for the inclusion of materials in the Clearinghouse. The beta website currently provides links to the following types of information:

- General newborn screening information
- Genetic Alliance Resource Repository, which is searchable online database of resources in the genetics community. It includes links to state newborn screening program homepages, conditions screened, and program contact information
- Peristats by March of Dimes
- Condition-specific information provided by the National Library of Medicine
- Regional Genetic and Newborn Screening Service Collaboratives

- National Newborn Screening Coding and Terminology Guide (NLM)
- National Newborn Screening and Genetics Resource Center
- NIH Research Portfolio Online Reporting Tool (RePORT)
- Newborn Screening Playlist on Genetic Alliance's YouTube Channel
- Newborn Screening Funding page
- NBSC Blog

A user poll, an RSS feed of newborn screening news pulled through Google Alerts, a list of the most recent NBSC Blog posts, and the BabysFirstTest Twitter feed are also featured on the site.

D. BabysFirstTest.org Website Objectives

The Clearinghouse of newborn screening information, as outlined in the *Newborn Screening Saves Lives Act of 2008*, is to be the central clearinghouse of current educational and family support and services information, materials, resources, research, and data on newborn screening. The goal of the website is to enable parents and family members of newborns, health professionals, research and industry representatives, and other members of the public to increase their awareness, knowledge, and understanding of newborn screening as a process and system, the conditions included in state newborn screening panels, and the tests used to screen for and confirm the conditions. The current architecture of the Clearinghouse (http://www.nbsclearinghouse.org) does not enable it to meet the needs of the newborn screening community and the public at large.

Genetic Alliance is seeking the services of a qualified and experienced firm to develop www.BabysFirstTest.org based upon this RFP and feedback related to www.nbsclearinghouse.org. Proposals should include front-end development, re-branding and design, interface with Genetic Alliance's existing database architecture, testing, and implementation. Genetic Alliance has already purchased the BabysFirstTest.org URL.

The Clearinghouse, which will be relaunched as BabysFirstTest.org at the conclusion of implementation of the RFP requirements, will provide a highly accessible, customizable, interactive, and user-friendly online resource that supplements current resources by aggregating, organizing, and harmonizing them in a meaningful, accessible way. The Clearinghouse will increase public understanding of NBS conditions and the criteria for which conditions are included in the uniform screening panel by:

- Creating centralized and public-facing materials that are cross-linked with those available on broad topics such as family planning, pregnancy, and the newborn period (benchmark to be determined through pre- and post- testing of impact of educational materials developed or utilized).
- Providing a centralized location for responses to news articles or other dialogues (i.e. myth busting and providing context for issues discussed).
- Creating resources for the wider health professional community (childbirth educators, nurse-midwives, doulas, prenatal care providers, family physicians, pediatricians, specialists, etc).

- Improving transparency in program and policy development on both the state and federal level. The Clearinghouse will provide easy access to agency reports and meeting minutes, in addition to consumer-friendly summaries.

This project will involve implementing a new information architecture that provides a customized experience for each of six user types:

1. Expectant Parents
2. Recent Parents
3. The Public
4. Health Professionals
5. Industry/Research
6. State Departments of Health

Genetic Alliance is interested in a dynamic, innovative design and architecture that engages site users and provides easy access to the information sought after. Implementation of a content management system will be imperative to provide Genetic Alliance with the ability to manage content.

E. BabysFirstTest.org Website Criteria

The Clearinghouse must adaptable to current and changing technology, provide content management capability for Genetic Alliance staff, and be used as a public communications tool. Internet Service Provider and hosting is not part of this contract. Genetic Alliance already has an ISP and web server; therefore, these services are not part of this RFP process.

The website shall meet the following criteria:

- Meet ADA requirements and Section 508 standards.
- Be compliant across browsers (Firefox, Internet Explorer, etc).
- Include recommendations to maximize usability on mobile devices (mobile friendly design, separate mobile site development, or mobile applications for certain features).
- Optimized for search engines.
- Include a comprehensive site architecture and site map.
- Graphic enhancements should be kept within reasonable size limits to allow for timely site loading. Further, the diverse audience of the Clearinghouse site will have access to Internet that is of varying speeds. A simpler, HTML version of the site must be made available to accommodate the information needs of users with slower Internet.
- Tracking tied into Google analytics by each page.
- Technologies implemented provide web administrators intuitive, easy-to-use staffing features and administrative interface/dashboards.
- Allow for printable forms using Adobe for opening and printing documents.
- User-friendly content management system (CMS) that includes staging features and easy-to-use interface for web administrators (see Appendix B for more information on backend compatibility). In addition, please include any staff qualifications necessary for updates and administration of the tool.

- Interface with Genetic Alliance's existing SQL-based integrated databasing system, central portal, and CRM. (See Appendix B for complete specifications).

F. Desirable Features

The following broad features are desirable for the new BabysFirstTest.org website:

- Customized user experiences for the user types outlined in Section II.D. Upon entering the website the individual should be prompted with a question asking him or her to identify him/herself as a particular kind of user. Content will be arranged specific to that user type's information needs. Please see Appendix A for content specific to each user type.
- Re-branding of site should be visually appealing and "family-friendly," utilizing a balanced mix of photos and images, interactive media, and text.
- Designed to be a clean and easy to navigate for various audiences. The website must also be flexible and expandable based on changing needs. Genetic Alliance welcomes design proposals from web developers but will also engage and consult with its own designer.
- The Clearinghouse project is a five-year cooperative agreement (Year 2 began on September 1, 2010), but it is hoped that the site will be sustained long after this five-year period. For the purposes of this contract, the firm should provide an information architecture that will support the Clearinghouse for a minimum of three years.
- Allow for interactivity. Include email, surveys, national and state maps, social media, feedback forms, and calendars. See interactive features in the next section for more information.
- Integration of video players and photo slideshow applications.
- It is hoped that many of the materials in the Clearinghouse will be able to be translated to Spanish and other languages later in the project. Any functionality built into the architecture that would enable seamless development and integration of a Spanish translation of components of the site, leading to the eventual translation of the entire site, would be desirable.

We encourage proposers to include other ideas for modules and enhancing the dynamics and interactivity of the site in their proposal. Any additional modules beyond the scope of this RFP should be clearly delineated in the proposed budget.

More specifically, there are six interactive features Genetic Alliance would like showcased on the Clearinghouse that will require pull-throughs from external sites. Further, for most features, a subscription capability where individuals may be notified of additions meeting particular keyword criteria should be built. The six interactive features include the following items:

1. ***Baby's First Test Blog*** – Genetic Alliance created the NBSC Blog on the existing Clearinghouse website to provide an open space for users to learn about topics in newborn screening, learn from one another, share personal stories, and brainstorm opportunities and challenges as addressed through posts. After logging into the Clearinghouse, readers can post comments on blog entries, which are monitored

by Genetic Alliance staff. To learn more, please visit the Clearinghouse blog: http://www.nbsclearinghouse.org/blog/1. For BabysFirstTest.org, implementation of a blog feature will include building upon content already generated in the blog on the NBSClearinghouse.org site, but the functionality and capacity must be greatly enhanced. Genetic Alliance would like the blog to be amenable to cross-postings with other parent and family blogs interested in discussing newborn screening and to funnel relevant conversations from other blogs into the blog frame.

2. ***RSS News Feed*** – Genetic Alliance is currently struggling to utilize terms in its Google Alerts that both keep the search results broad enough to be applicable to diverse families and communities while ensuring the results are of a high quality and still relevant to the newborn screening community. As such, the RSS news feed on the current NBSClearinghouse.org website can at times include results inappropriate for the intended community. Development of a refined searching process will ensure high quality and appropriate results are displayed on the website.
3. ***BabysFirstTest Twitter Feed*** – Genetic Alliance created the BabysFirstTest Twitter username as an initiative of the Clearinghouse to provide interested stakeholders updates on the progress of the Clearinghouse project. It also serves to engage the broader public on hot topics in newborn screening. Twitter enables the Clearinghouse to establish relationships with members of the public and identify parent blogs and discussion forums to eventually integrate the Clearinghouse into existing models for sharing information. To date, Genetic Alliance has not developed a consistent strategy to raise awareness of the Twitter username and engage additional followers with the exception of highlighting the username on its website and staff members frequently 'tweeting' from the account while attending meetings in the community and highlighting important newborn screening news. To learn more, visit http://www.twitter.com/babysfirsttest. Integration of the BabysFirstTest Twitter username into the new site will include development of an attractive display of BabysFirstTest Twitter posts and follower retweets on the Clearinghouse webpage.
4. ***Genetic Alliance Newborn Screening YouTube Playlist*** – Genetic Alliance established the newborn screening playlist on its YouTube channel in April 2010 and since has received positive reviews. The playlist includes videos developed by the newborn screening community and it is intended to be an interactive platform to aid individuals in learning about newborn screening. It originally included about 20 videos on general topics in newborn screening, but was recently expanded to include disease-specific videos, totaling nearly 30 videos. Please visit the playlist to learn more: http://www.youtube.com/geneticalliance#g/c/A6C56724C998F799. BabysFirstTest.org should include pull-throughs of content-specific newborn screening videos or new additions to the Newborn Screening YouTube Playlist.
5. ***State Editable Section*** – State Departments of Health must have password restricted access to a "State Editable Section" of the Clearinghouse website in order to input information specific to their programs that are to be made available to the public. Genetic Alliance backend architecture will fully support user

permissions-based access. This RFP includes the interface with that system rather than creation of database architecture itself. This section must have pre-determined data fields connected to Genetic Alliance's CRM that can be categorized, sorted, and time-stamped to generate reports and analyze across programs. The system must be able to automatically generate email alerts to programs with data that has not been updated in 12 months or more, or if new fields are created that must be completed, requesting for the program to visit the site to input the required updated or new information.

6. ***Form Emails*** – Regardless of user type, users of the Clearinghouse website must have easy access to an online form (for example, via a Contact Us link) for individuals to submit feedback on their user experience or content they would like featured on the site.

In addition to the development of the six interactive features above, Genetic Alliance will release a separate development project for the creation of an interactive **Events Calendar**. This project will include the development of a community calendar that is searchable by key word or date and would allow individuals who have logged into the site to propose events for addition. As the architecture for the events calendar would need to be linked to Genetic Alliance's backend database (see Appendix B) and be integrated into Genetic Alliance's numerous web projects, development of the events calendar is not a part of this RFP.

Finally, while the website experience is intended to be customized to the user type the user selects upon entering the site, it is crucial that the user at any time be able to switch between user types or be able to access information that may not be readily available in one user type but by definition is readily available in another user type. However, while the goal of the site is to have a customized experience based upon user type, it is important that all non-restricted information be available to all users.

IV. PROPOSAL REQUIREMENTS

All written proposals will be reviewed and evaluated based on how well they address the specific needs of Genetic Alliance as outlined in this RFP. Genetic Alliance may choose to use competitive negotiations to develop the final contract or agreement with the proposer whose proposal best suits the needs of Genetic Alliance, based upon the sole discretion of Genetic Alliance.

Mandatory specifications will be evaluated on a Pass/Fail basis. Any proposal that fails to meet any single mandatory specification or requirement will be deemed non-responsive. Proposers who meet mandatory specifications or requirements will then have their responses evaluated as to how the proposer's solution meets the required specification or requirement.

A. Mandatory Requirements

Proposers must provide the following mandatory information. Failure to provide this

information may be cause for the proposal to be rejected.

1) The title page of the proposal must contain the firm's name, address, telephone number, fax number, principal contact, website URL, and e-mail address.
2) The proposal shall identify the website firm and describe the experience of the staff who will work on the website. The proposal must also identify expected time on site for each staff member.
3) Proposers shall provide resumes identifying the education, experience, and certifications held by each professional staff member listed under subsection (2) above and noting their roles and responsibilities for the proposed project.
4) The proposal should include necessary software and hardware, any additional communication requirements, integration needs, and potential costs necessary to develop the site.
5) The proposal should be all encompassing, with a single vendor identified as the "responsible lead vendor." Please indicate any needed subcontracted services required to meet the needs of the proposal or clearly indicate what portion of the services are not included as part of your proposal.
6) The proposal should include an estimated summary timeline for completion of each phase of the project. This should be as realistic as possible since this will be part of the contractual agreement.
7) A detailed work plan describing the firm's approach to designing, managing and coordinating this project. The description should include all tasks listed in the scope of work for all phases of the project and a tentative schedule.
8) Collection of information. Please state how you intend to gather all the required information, format preferred, and assistance expected from Genetic Alliance in order to complete this project.
9) Years of experience related to website development. Provide a list of comparable websites, including the website address, company/agency contact person, address, telephone number, and hard copies of the Home Pages. These companies/agencies may be contacted for references.
10) Proposers shall provide a minimum of three (3) references where similar services in scope to the requirements of this RFP have been provided. Enclose a section on relevant website development experience and information on the extent of your firm's abilities to meet the needs of this project.
11) The proposal should contain 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 must be clearly stated.

B. Quality of Website Development Approach

1. Describe the proposer's understanding of website development, design, and implementation services to be provided, the approach to the engagement, and the overall work program, including a timeline.
2. Describe how the proposer's website redesign approach will comply with industry and compliancy standards and supply adequate internal control beyond implementation.
3. Describe the proposer's ability to provide specialized technology to support the

website's functionality and appeal.

C. Staffing of Website Development

1. Describe the proposer's ability to staff website engagements within the time schedules of this RFP.
2. Describe the proposer's ability to staff the website development engagement with professional personnel.
3. Describe the professional staff responsible for this engagement.
4. Describe the proposer's organizational structure.

V. METHOD OF EVALUATION AND AWARD

The evaluation and selection process is intended to identify the proposer best qualified to conduct the website development. Selection will be based on an evaluation of the proposer's ability to meet the established criteria as set forth in this RFP.

An evaluation team composed of Genetic Alliance representatives will review the proposals. The criteria listed below will be used to evaluate proposals for the purpose of ranking them in relative position based on how fully each proposal meets the requirements of this RFP.

A. Evaluation Criteria

The website redesign RFP evaluation shall be based on the following criteria:

Evaluation Criteria	Points
Mandatory Requirements	Pass or Fail
Quality of Website Approach	200 points
Depth of Firm Experience	100 points
Staffing of Website Development	50
Cost	150
Total Maximum Possible Points	*500*

VI. OTHER INFORMATION

A. Signature Block

All proposals must be signed by an authorized agent of the firm. Any firm or individual submitting a signed proposal shall be deemed to have read and understood all the terms, conditions, and requirements of this Request for Proposal.

B. Withdraw Proposal

Proposers may withdraw their proposal at any time prior to final awarding of contract.

C. Discussions/Negotiations

Genetic Alliance reserves the right to conduct discussions with proposers, to accept revisions of proposals, to negotiate price changes, or to negotiate separately with any source whatsoever if no acceptable proposals are submitted in order to be serve the interests of Genetic Alliance.

D. Award

The award, if any, shall be made to the responsible proposer whose proposal is determined to be the most advantageous to Genetic Alliance based on the evaluation factors described in the Request for Proposal. Price, although a consideration, may not be the sole determining factor. Genetic Alliance reserves the right to ask for "The Best and Final Offer."

E. Contract Contingency

This RFP is made for information and/or planning purposes only and does not obligate or bind Genetic Alliance contractually to accept any proposal submitted. The final award is expressly contingent upon the successful negotiation of a contract with Genetic Alliance.

VII. SIGNATURE BLOCK

Please return this page with each copy of your submittal.
The undersigned, an authorized agent of his/her company, hereby certifies:
( ) familiarization with all terms, conditions, and specifications herein stated;
( ) vendor is qualified to perform work and services as included;
( ) that the pricing contained in this submittal is valid until _____ (date).

_____	_____
_____	_____
_____	_____
Company Name	Authorized Signature
_____	_____
Mailing Address	Printed Name
_____	_____
City, State, Zip Code	Title
_____	_____
Federal Employer ID Number	Phone Number
_____	_____
Is Business a Corporation?	Fax Number
_____	
Email Address	

APPENDIX A:

BabysFirstTest.org Content & Features

Audiences as specified by the legislation:

1. Expectant parents
2. Recent parents (including those with a child with a diagnosis)
3. Members of the public
4. Health professionals
5. Industry representatives
6. Researchers

Content needs by audience

The following represents information sources to be presented in BabysFirstTest.org for each user type. This list is not meant to be all-inclusive, and Genetic Alliance reserves the right to request the inclusion of additional content and features for presentation of the information on the site.

1. Expectant Parents

- General information about NBS – website summary and printable brochures
    - *Information would be presented utilizing a balanced combination of multimedia, static content, and resources pulled through the Resource Repository*
- Information about supplemental screening – what it is, why it may be of interest, how to access it
    - *Information would be a presented through static content, an interactive laboratory listing with link outs, and resources pulled through the Resource Repository*
- State-specific information about screening panels
    - *Information would be presented through interaction with various external sites, including the National Newborn Screening Information System (http://nnsis.uthscsa.edu/xreports.aspx?XREPORTID=5), Peristats (http://www.marchofdimes.com/peristats/), and the Resource Repository, with hopes of information being embedded in BabysFirstTest.org*
- What to expect from the NBS process – from heel prick to abnormal results through short-term follow-up
    - *Information presented through static content*
- Consumer Focused Newborn Screening checklist for communicating with a provider around an abnormal screen result
    - *Information presented through static content*
- NBS in the news
    - *Utilize an RSS feed and also an interactive feature allowing individuals, namely the Clearinghouse staff, to add context and notes to stories*
- Residual dried blood spot storage and use
    - *Information presented through static content (fact sheet)*
- Information about opting-out of NBS and residual dried blood spot storage and use

    - *Information presented through static content*
- Who to contact with questions about NBS
    - *Extensive linking with the National Newborn Screening and Genetics Resource Center (http://genes-r-us.uthscsa.edu/)*
- Videos of parent experiences with NBS/the importance of NBS
    - *Embed videos from the Genetic Alliance NBS YouTube Playlist*
- FAQ – should include how NBS tests are paid for (insurance)
    - *Information presented through static content*

2. Recent Parents

- General information about NBS – website summary and printable brochures
    - *Information would be presented utilizing a balanced combination of multimedia, static content, and resources pulled through the Resource Repository*
- Information about supplemental screening – what it is, why it may be of interest, how to access it
    - *Information would be a presented through static content, an interactive laboratory listing with link outs, and resources pulled through the Resource Repository*
- State-specific information about screening panels
    - *Information would be presented through interaction with various external sites, including the National Newborn Screening Information System (http://nnsis.uthscsa.edu/xreports.aspx?XREPORTID=5), Peristats (http://www.marchofdimes.com/peristats/), and the Resource Repository, with hopes of information being embedded in BabysFirstTest.org*
- Disease-specific information, including lists of support groups and list of common specialists a family may need to see for a particular condition
    - *Information to be presented through embedding of Disease InfoSearch (http://www.geneticalliance.org/dis) adaptation*
- List of five conditions that have the highest false-positive rates
    - *Information to be presented through static content*
- Information about false positives, false negatives, inconclusive findings, carrier identification
    - *Information to be presented through static content and resources developed by the National Newborn Screening and Genetic Resource Center*
- State specific list of services
    - *Information to be presented through information submitted through state editable section*
- Information about short-term follow-up and long-term follow-up – how parents are contacted with the results of the screen, through roles of provider
    - *Information to be presented through static content*
- Information that is complementary to ACMG ACTion Sheets and confirmatory algorithms – what to do in lay-friendly terms for getting your child ready for the confirmatory test
    - *Information to be presented through static content*
- What to do when a family member is diagnosed with a condition
    - *Information to be presented through static content*

- Link to state departments of health
    - *Information to be presented through static content*
- Policies surrounding storage and use of residual dried blood spots
    - *Information to be presented through static content*
- FAQ – should include how results will be reported to parents and how newborn screening is paid for by insurance
    - *Information to be presented through static content*
- NBS in the news
    - *Utilize an RSS feed and also an interactive feature allowing individuals, namely the Clearinghouse staff, to add context and notes to stories*

3. *Members of the public (this section should also engage the media)*
- General information about NBS – website summary and printable brochures
    - *Information would be presented utilizing a balanced combination of multimedia, static content, and resources pulled through the Resource Repository*
- State-specific information about screening panels
    - *Information would be presented through interaction with various external sites, including the National Newborn Screening Information System (http://nnsis.uthscsa.edu/xreports.aspx?XREPORTID=5), Peristats (http://www.marchofdimes.com/peristats/), and the Resource Repository, with hopes of information being embedded in BabysFirstTest.org*
- NBS in the news
    - *Utilize an RSS feed and also an interactive feature allowing individuals, namely the Clearinghouse staff, to add context and notes to stories*

4. Health professionals
- Seven things parents want to know about NBS (http://mchb.hrsa.gov/pregnancyandbeyond/newbornscreening/)
    - *Information to be presented through static content*
- ACMG ACTion Sheets and confirmatory algorithms (http://www.acmg.net/AM/Template.cfm?Section=NBS_ACT_Sheets_and_Algorithms_Table&Template=/CM/HTMLDisplay.cfm&ContentID=5072)
    - *Information to be presented through static content*
- Support services for patients
    - *Information to be presented through embedding of Disease InfoSearch adaptation*
- Prevalence for each condition screened for in NBS and the risks of receiving an abnormal result
    - *Information to be presented through linkage with Peristats*
- NBS panel in each state
    - *Information to be presented through linkage with the Resource Repository and the National Newborn Screening and Genetics Resource Center.*
- State protocol with regard to how the provider will receive/learn the result
    - *Information to be provided through inputs from the state-editable section*
- Contacts in the state department of health (laboratory and follow-up personnel)
    - *Information to be presented as a pull-through from the National Newborn Screening and Genetics Resource Center*

- Information about ongoing research studies
    - *To be determined*
- Information on state residual dried blood spot storage and use practices
    - *Information to be delivered through static content and report from state editable section.*
- Lists of specialists in each state
    - *Information to be delivered through reports generated from state editable section*
- NBS in the news
    - *Utilize an RSS feed and also an interactive feature allowing individuals, namely the Clearinghouse staff, to add context and notes to stories*

5. *Industry representatives/researchers*
    - Information on the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children and national policymaking
        - *Content to be presented through blog discussion generated by Clearinghouse staff and spotlight features on homepage.*
    - Research grant and funding opportunities
        - Information to be generated through pull throughs of Scan Grants opportunities (http://www.scangrants.com) and Grants.gov (http://www.grants.gov)
    - Prevalence of conditions included in NBS
        - *Information to be presented through embedding information from Peristats and the National Newborn Screening Information System*
    - Information about ongoing research studies
        - To be determined
    - Testing methodologies for different conditions as used in different states
        - *Information to be presented through embedding information from the National Newborn Screening Information System*
    - Newborn Screening Coding and Terminology
        - *Information to be presented through linkages with the National Library of Medicine (http://newbornscreeningcodes.nlm.nih.gov/)*

APPENDIX B:

Summary of Genetic Alliance Portal Environment and Application Development Requirements

I. Background Information

A. What Is The GA Portal?

The Genetic Alliance Portal is an application cluster that works as an interconnected framework for multiple websites and applications maintained by Genetic Alliance. At the moment four of Genetic Alliances websites are part of this system, more websites are being updated to be part of this portal in a continual effort to bring all of Genetic Alliance web applications under the portal environment.

The four websites currently part of the portal are:

1. Genetic Alliance www.geneticalliance.org
2. Resource Repository www.resourcerepository.org
3. Newborn Screening Clearinghouse www.nbsclearinghouse.org
4. Does it Run in the Family? www.familyhealthhistory.org

There is a central portal application tying these websites together - http://portal.geneticalliance.org.

Like any portal system, the GA Portal shares core assets and functions making it possible for multiple websites to leverage GA resources. At the moment, user authentication (registration, login and user roles assignment) and user management is the central part of the portal allowing users to register and/or login once to access any of the four target sites.

Current development efforts are on the way to bring additional core shared objects such as the Genetic Alliance's "organization" entity and additional websites into the portal environment. Eventually, all existing Genetic Alliance websites will be part of the portal - sharing data, communicating with each other and allowing centrally driven administration and management of the websites and associated resources and assets.

B. Technical Details

DATABASE

The portal and its target websites share a single database. Tables in this database are marked by their roles using naming conventions and table prefix.

› **Prefix "tbl_"**: all tables that must be shared amongst the target websites (core shared objects) start with the prefix "**tbl_**"

› **Local Prefixes**: tables that are strictly local – needed only for the functionality of a

specific website start with a unique prefix related to that specific website. As an example, "**fhht_**" for the Family Health History (Does it Run in the Family) website and "**rr_**" for the Resource Repository.

ENVIRONMENT

System: Linux
Web Server: Apache
Language: PHP 5
Database: MySQL
Framework: * Relatively open

* The central Portal website utilizes an Object Oriented and multilayered (MVC) framework called Yii. Each of the existing applications utilized a different framework or used the traditional non-OOP PHP programming interfaces when they were originally developed. However, for standardizing the system, as a general standard all new websites must follow OOP architecture. And as a programming model, MVC or other design vs. data and logic separation models should be implemented. There is no specific requirement to adhere to a single PHP framework as long as the general standard is maintained.

II. Requirements for New Application Development

The primary requirement for any new application development for Genetic Alliance is that the application is developed and launched as part of the portal environment from the very start eliminating the need for a conversion after the application is launched.

The team/vendor responsible for developing new application must research and collect all necessary details for compliance, take the necessary steps and enforce precautions to ensure that the new application is seamlessly integrated with the portal.

Any framework, platform, model or other programming choices and approaches must not prohibit or be counter intuitive to the portal's current workflow and future growth.

SYSTEM

+ LAMP based development - Linux, Apache, MySQL and PHP

DATABASE

+ The new application's tables should reside within the portal database sharing the global schema.
+ The local tables must start with an unique prefix i.e. "acronym_"
+ New additions to the core shared tables should bare the prefix "tbl_" and must be reviewed and approved by Genetic Alliance (ProjectMiso) Data Modeler.
+ Use existing tables for shared objects such as users and organizations; more are being added to this list

+ AVOID and ELIMINATE data redundancy – data that already exists should not be duplicated in new tables. This type of data include both -

- Core shared entities such as users and organizations, and
- Target website data such as resources in the resource repository, diseases in the Disease InfoSearch and other

APPLICATION

Framework and Platforms

+ Use OOP architecture preferably with an n-tier model like MVC or other code vs. design separation

+ DO NOT use of third party CMS systems such as Drupal or Joomla, that create their own database architecture including core objects such as users and authentication systems forcing a parallel system to the GA Portal

+ The Yii framework is preferred but not required

Application Centralization

+ Like the existing target applications, the new applications will use the CRM system for its user related needs – from login and authentication, to registration, user role assignment and user management by admin and profile management by end users

+ Ideally, the administration interfaces of the new website should be built by extending the GA Portal website's UIs without changing the portal's framework or architecture.

Sharing Resources, Features, and Data

+ To avoid redundancy by sharing application data, logic and resources

+ Use existing sharing applications, such as the Resource Repository webservice for the Resource Repository data, for sharing data that are not local to the new application

+ If new webservices are needed for data sharing needs for any new websites or applications, please bring that to Genetic Alliance's attention before development

Content and Translation

+ It would be ideal if the new application is built with an architecture that has a multilingual capacity.

+ Preferably, the static content (text, labels, messages ,etc.) on the site should externalized to language files (PO or PHP) so it makes translation and content updates easy and standardized, if and when translation and content update needs arise.

DEVELOPMENT ENVIRONMENT

Production and Staging Environment

All applications maintained by Genetic Alliance are developed locally by developers in their systems and then regularly uploaded to the staging environment.

Each staging site should be completely separate from the production environment by separating physical location and the database to store data.

The separate physical server paths and database names and credentials will be provided during development.

Before finalization, new applications must be tested fully and debugged in the staging environment before making it public in the production environment.

Version Control

All new website should create a Subversion (SVN) repository at its physical location to maintain version control. Developers should regularly (daily or weekly) commit their work both for safety (back up) as well as maintaining good history of work.

APPENDIX C:

Schedule of Deliverables and Costs

The cost schedule shall set forth all estimated costs for providing the services for the website development. Costs shall be expressed as total cost for Genetic Alliance. Costs shall include all costs to Genetic Alliance, including travel and other out-of-pocket expenses. For each deliverable delineated below, proposers must specify the **total hours, hourly rate, appropriate equipment and/or licensing costs, and total costs**.

Genetic Alliance shall assume the proposer will provide the following deliverables at the following times:

1. **Conduct a thorough analysis and opinion of both current NBSClearinghouse.org website and its limitations, as well as vision for BabysFirstTest.org**
   The analysis should include meetings with various representatives at Genetic Alliance and review of feedback from key partners in the Clearinghouse project, namely the project Steering Committee, the National Advisory Committee, and the Materials Working Group. Review of feedback can be conducted through a combination of review of meeting minutes and summaries (furnished by Genetic Alliance upon contract signing) and through interviewing key Genetic Alliance representatives. The opinion will be presented to Genetic Alliance for consideration and approval. The research phase for BabysFirstTest.org should include discussion of favorable website examples.

2. **Development of Comprehensive Site Architecture**
   Draft and present a comprehensive site architecture plan for the BabysFirstTest.org website, including proposed navigation format.

3. **Presentation of Proposed Website Design**
   The proposed website design will highlight the new design and application of dynamic content, showcase how the content management system will best meet the needs for Genetic Alliance, address any integration with current technologies, with special attention to the six interactive features outlined in section III(F), and emphasize the advantages to the website users. The website must meet ADA requirements, cross-platform compatibility, and mobile accessibility. The presentation will be attended by several Genetic Alliance representatives and the Health Resources and Services Administration project officers for the cooperative agreement, at minimum. The firm must also be prepared to provide a presentation of the proposed website design via slideshow to the project National Advisory Committee via a private, though interactive, webinar (2 hours).

4. **Progress Reports**
   Throughout the website design process the Firm should supply Genetic Alliance with progress reports on activities occurring. Regular meetings will be scheduled at the Firm's and Genetic Alliance's discretion to review status and action items to keep the project moving forward.

5. **Testing of New Site**
   In order to ensure that the BabysFirstTest.org site truly increases newborn screening knowledge and awareness for the diverse audiences for which it is built and that it meets the usability and navigation requirements of its audiences, the Firm must build into the timeline for the project a plan to conduct pre- and post-testing of the site and how the information is accessed. Testing and feedback may be obtained through focus groups (the participants of which Genetic Alliance may recruit); limited access to a password protected staging site by the project Steering Committee, National Advisory Committee, Materials Working Group and Public Education Working Group; and presentations of components of the site (for example, a particular feature) or for particular users through webinar technology, for which the Firm is expected to present, lead conversation, and integrate feedback. For all forums in which feedback is given, either vocally or in writing, the Firm must detail how the feedback was taken into account and collaborate with Genetic Alliance to prioritize the integration of the feedback into the BabysFirstTest.org appearance or architecture. **Genetic Alliance hopes that a test version of the BabysFirstTest.org website, at least in appearance, may be ready for presentation to its community by the Genetic Alliance Annual Conference, June 23-26, 2010 in Washington, DC, either as a workshop or special plenary session.** If the Firm can meet this deadline, the Firm will train Genetic Alliance staff to give the presentation and the Firm will attend the Annual Conference to receive feedback on the site.

6. **Training of New Site**
   On-site testing and training shall occur prior to final presentation of the new website design. The training will include any Genetic Alliance representatives who have access to updating content and the administrators. The Firm will provide reference documents with instructions for completing tasks.

7. **Presentation of New Site**
   The firm will conduct a final presentation of the site to Genetic Alliance and the project Steering Committee.

8. **Exit Conference after Conclusion of Project**
   The Firm will meet with Genetic Alliance representatives on-site for a final review of the site two to four weeks after the launch. These discussions should address any issues that have occurred since the launch and any final instructions to the Genetic Alliance website administrators. **This meeting will occur no later than September 1, 2011.**

9. **Working Paper Retention and Access to Working Papers**
   A set of working papers outlining the technology used in the new design, all coding, contracts, and contact information for vendors to address any issues going forward, implementation steps and instructions for reference, and any special access or reference documents for transitioning the site maintenance to Genetic Alliance website administrators should be provided at the exit conference.