Heartland Genetics and Newborn Screening Collaborative Annual Conference
August 25, 2011

Vision

- Connect parents and healthcare providers with resources and information
- Improve understanding and informed decision-making
- Facilitate information sharing

*Highlight the benefits of screening for the public

What the NBS Saves Lives Act Requires

- Centralized and online
- Research-based information
- Information on each state
- Interactive forum
- Data (APHL)
- Dissemination

Partners and Projects: Who's involved

- Professional Groups (ACMG, NSGC, AAP, etc.)
- State Health Departments (APHL, Genetics Collaboratives)
- Healthcare Providers
- NBS and Consumer Advocates
- Health Education Experts
- Other NBS Stakeholders (March of Dimes, etc.)

www.BabysFirstTest.org

- Current
  - Link to Partners
  - Condition specific information – condition description, GARD, ACT Sheets, NCBI portal, Disease InfoSearch
  - Immune Deficiency Foundation blogging partnership
- New Site (September 2011)
  - General Information (prenatal and after screen)
  - Healthcare Provider section
  - Multi-media

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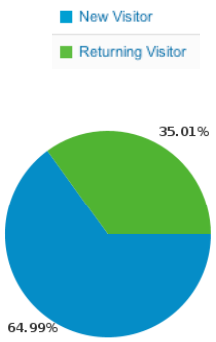
www.nbsclearinghouse.org

Beta Site Analytics

- 1,808 visits in the last three months
  - 778 more than the previous quarter
  - Average 18.83 visits per day
  - 50 countries and territories
- 1,268 unique visitors
- 48 visits from mobile devices
- Average time on site = 2:13



Beta Site Analytics

Most Popular Content

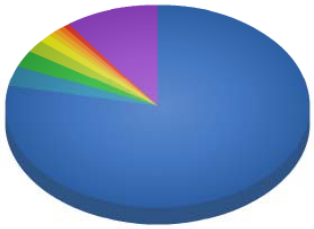
- Homepage = 1,416 page views
- About page = 279 page views
- Condition Specific Information = 201 page views
- Blog = 181 page views

Social Media

- NBS YouTube Videos
  - Connect facts/policy to stories (Media and DSO)
  - Highlight partners – increase visibility
- Twitter (@babysfirsttest)
  - Chats- raise awareness
  - March of Dimes, APHL
  - New followers- new networks
- Blog
  - Give people discussion space
  - Connect other partners

Social Media

Clicks by Region



Region	Clicks
United States	78.1% (118)
Canada	3.3% (5)
European Union	2.6% (4)
Spain	2% (3)
India	1.3% (2)
United Kingdom	0.7% (1)
France	0.7% (1)
Turkey	0.7% (1)
Australia	0.7% (1)
Others	9.9% (15)

Lists following BabysFirstTest

- @fragilexsyndrom/disability
- @APHLNews/newborn-screening
- @nacersano/beb
- @APHLNews/paper-li-16
- @davinbintang/deaf-information
- @short_of_breath/news
- @HelpHarriet/worldwide-health
- @CrunchyNavyWife/metabolic-disorders-2
  Resources for/families with fatty acid oxidation disorde & inborn errors of metabolism
- @BabysFirstTest/nbs-organizations
- @BabysFirstTest/genetics-newsfeed
- @Tash1210/genetics

www.BabysFirstTest.org

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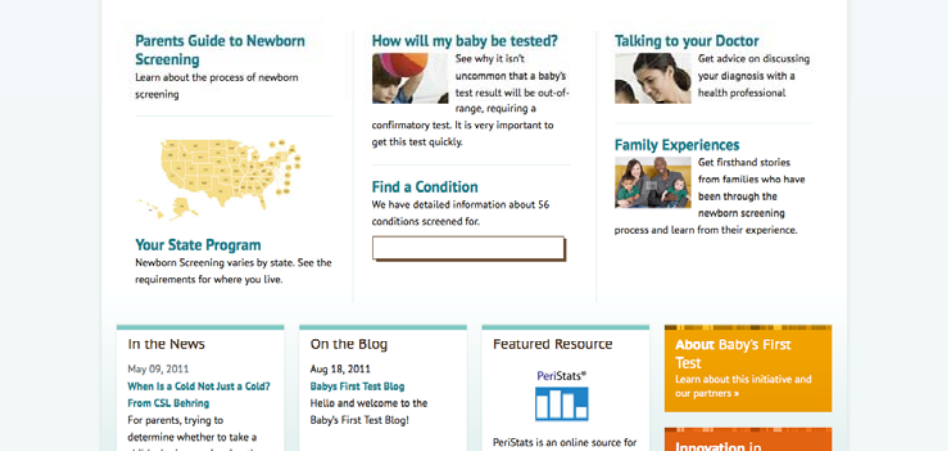

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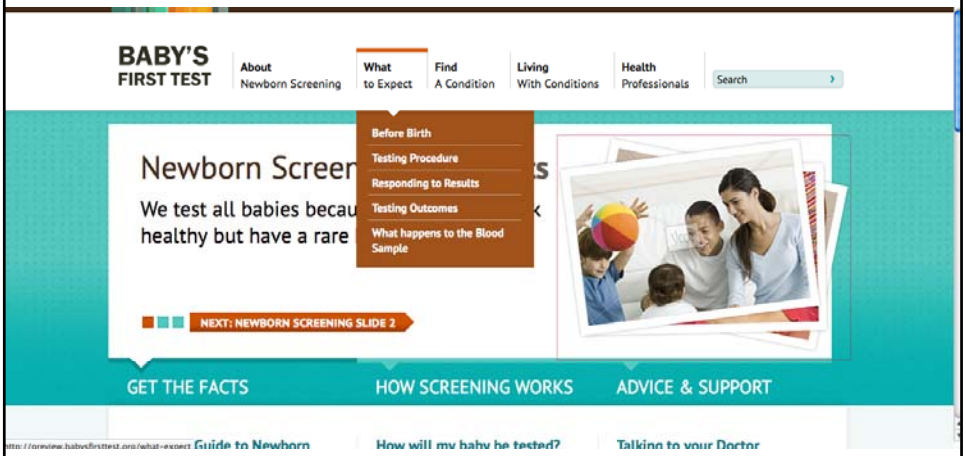

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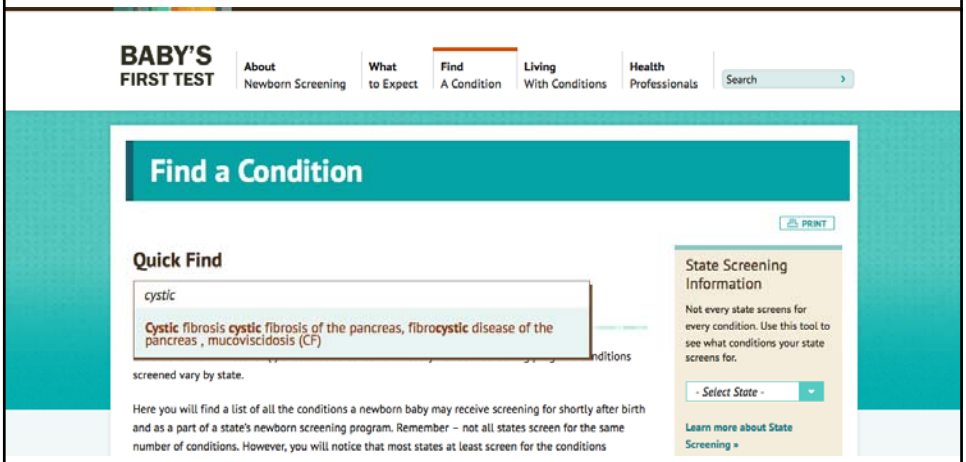

About Cystic fibrosis

Early Signs | Treatment | Expected Outcomes | Causes

Signs of cystic fibrosis (CF) usually start shortly after birth. Some signs may not appear right away. This is why early screening and identification is so important.

Early signs of CF include:

- Salty sweat; many parents notice a salty taste when kissing their child
- Poor growth and weight gain (failure to thrive)
- Constant coughing and wheezing
- Thick mucus or phlegm
- Greasy, smelly stools that are bulky and pale colored

If your baby shows any of these signs, be sure to contact your baby's doctor immediately

Support for Cystic fibrosis

Support Services | Accessing Care | Families' Experiences

Support groups can help connect families who have a child or other family member affected with cystic fibrosis with a supportive community of people who have experience and expertise in living with the

www.BabysFirstTest.org

BABY'S FIRST TEST

About Newborn Screening | What to Expect | Find A Condition | Living With Conditions | Health Professionals | Search

About Newborn Screening | **Conditions Screened By State**

PRINT

Screening Facts
Genetics & Family History
Screening Resources
Conditions Screened by State

Alaska

In this Section:

- What conditions are screened for in Alaska?
- About Newborn Screening in Alaska
- Policies and Resources

What conditions are screened for in Alaska?

Contacts

Newborn Screening Program Contacts

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Project and Partners: CHALLENGE AWARDS

- Purpose: Engage the community in the Clearinghouse and integrate it into existing outreach, engagement, or educational efforts
- Projects to be completed in a six month period
- Submitters could apply for up to $25,000 of funding
- Proposals due March 11, 2011
- Selected awardees notified April 1, 2011
  - March of Dimes
  - NYMAC
  - Hawai'i Department of Health
  - APHL

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Challenge Award Recipient	Project Summary
March of Dimes	Develop and disseminate, as part of its ongoing "Healthy Pregnancy, Healthy Babies" series, a five-minute English and Spanish-language **video vignette** depicting a discussion of NBS in a prenatal office visit setting.
NYMAC	Develop and pilot an educational toolkit to be used by nurse midwives, doulas, and other **childbirth educators** to introduce NBS into childbirth education and literature produced for expectant parents.
Hawai'i Department of Health	Conduct survey outreach with Asian and Pacific Islander families in Hawai'i on their **NBS information needs**, via electronic surveys/questionnaires at the Hawai'i Baby Expo and **Hawai'i WIC clinics;** Conduct focus groups to evaluate the BabysFirstTest.org website.
APHL	Develop a **video detailing the NBS process at a state public health laboratory** to de-mystify the testing process; Conduct outreach for BabysFirstTest.org via social media and partnerships with state departments of health.

Baby's First Test Staff

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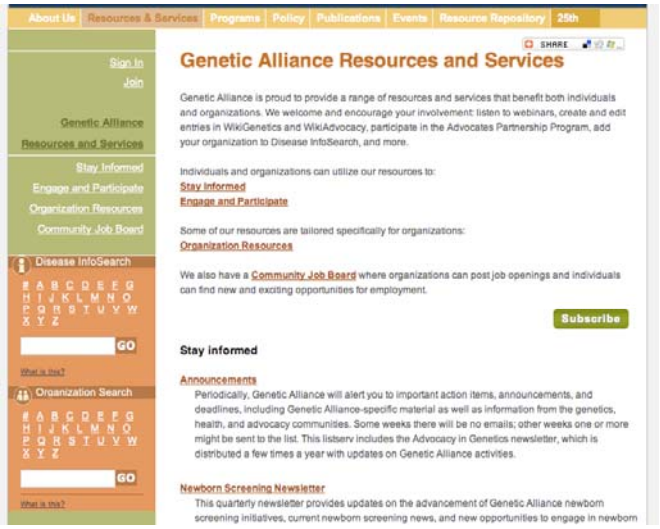
www.geneticalliance.org

www.geneticalliance.org/resources



www.wikiadvocacy.org

www.biobank.org

Please click here to view a PDF description of the GARB Toolbox.

Where do I begin?	What is a biobank?	Guidelines for considering a registry/biobank	Advocates are leaders in biobanking	
How do I make this a reality?	Registry/ repository start-up guide	Making your organization's biobank a reality	Genetic Alliance registry/repository boot camps	
Is my organization ready?	Organizational readiness checklist	Biobank question & answer session		
How do I select a vendor?	Vendor assessment summary	Vendor assessment worksheet	Landscape analysis manuscript	
Considering Genetic Alliance?	Genetic Alliance BioBank	GARB FAQs	Virtual tour of Genetic Alliance registry solutions	GARB history manuscript
What else do I need to know?	Biobank governance	Biobank governance checklist	Resource list	
How do I stay current?	Registry and Biorepository Bulletin	BioBank discussion listserv	BioBank Ambassadors mentoring	Weekly tips

Publication *Training/mentoring* *Videos* *Webinar* *Webpage* *Worksheet*

Next

Thank you!

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Genetic Alliance