



## 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**

 **NBSC**  
Newborn Screening Clearinghouse *Beta*

Home | Blog | F.A.Q. | Contact

**Account**

Sign In

Register

The Clearinghouse is under construction.

Your feedback is welcome!

**Quick Links**

- About the Clearinghouse
- How to Use This Site
- General Information
- Search for Resources
- Peristats by March of Dimes
- Condition Specific Information
- Get to Know Your Regional Collaborative

**Featured Resources**

Condition Specific Information

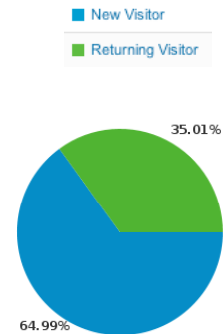


The National Center for Biotechnology Information at the National Institutes of Health (NCBI-NIH) and Genetic Alliance have collaborated to produce a web-based portal that combines information provided by the condition-specific community with numerous educational resources at NIH. This resource is currently undergoing a considerable remodel, so check back frequently.

[Click here to learn more.](#)

## 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

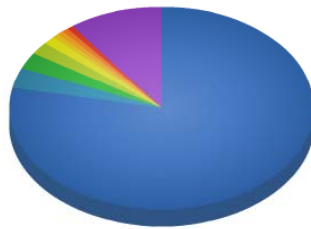
- Homepage = 1,416 page views
- About page = 279 page views
- Condition Specific Information = 201 page views
- Blog = 181 page views

## 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
-  @inacersano/beb
-  @APHLNews/paper-ii-16
-  @davinbintang/deaf-information
-  @short\_of\_breath/news
-  @HelpHarriet/worldwide-health
-  @CrunchyNavyWife/metabolic-disorders-2  
*Resources for families with fatty acid oxidation disorders & inborn errors of metabolism*
-  @BabysFirstTest/nbs-organizations
-  @BabysFirstTest/genetics-newsfeed
-  @Tash1210/genetics

# www.BabysFirstTest.org

**BABY'S  
FIRST TEST**

About  
Newborn Screening

What  
to Expect

Find  
A Condition

Living  
With Conditions

Health  
Professionals

Search

## Newborn Screening: The Facts

We test all babies because a few babies look healthy but have a rare health problem.



NEXT: NEWBORN SCREENING SLIDE 2

GET THE FACTS

HOW SCREENING WORKS

ADVICE & SUPPORT

# www.BabysFirstTest.org

### Parents Guide to Newborn Screening

Learn about the process of newborn screening



### Your State Program

Newborn Screening varies by state. See the requirements for where you live.

### How will my baby be tested?

See why it isn't uncommon that a baby's test result will be out-of-range, requiring a confirmatory test. It is very important to get this test quickly.

### Find a Condition

We have detailed information about 56 conditions screened for.

### Talking to your Doctor

Get advice on discussing your diagnosis with a health professional

### Family Experiences

Get firsthand stories from families who have been through the newborn screening process and learn from their experience.

### In the News

May 09, 2011  
**When is a Cold Not Just a Cold?**  
From CSL Behring  
For parents, trying to determine whether to take a

### On the Blog

Aug 18, 2011  
**Baby's First Test Blog**  
Hello and welcome to the Baby's First Test Blog!

### Featured Resource



PeriStats is an online source for

### About Baby's First Test

Learn about this initiative and our partners >

# www.BabysFirstTest.org

**BABY'S FIRST TEST** About Newborn Screening What to Expect Find A Condition Living With Conditions Health Professionals Search

## Newborn Screening

We test all babies because they are healthy but have a rare condition.

- Before Birth
- Testing Procedure
- Responding to Results
- Testing Outcomes
- What happens to the Blood Sample



NEXT: NEWBORN SCREENING SLIDE 2

GET THE FACTS HOW SCREENING WORKS ADVICE & SUPPORT

[Guide to Newborn](#) [How will my baby be tested?](#) [Talking to your Doctor](#)

# www.BabysFirstTest.org

**BABY'S FIRST TEST** About Newborn Screening What to Expect Find A Condition Living With Conditions Health Professionals Search

## Find a Condition

PRINT

**Quick Find**

cystic

**Cystic fibrosis** cystic fibrosis of the pancreas, fibrocystic disease of the pancreas, mucoviscidosis (CF)

screened vary by state.

Here you will find a list of all the conditions a newborn baby may receive screening for shortly after birth and as a part of a state's newborn screening program. Remember – not all states screen for the same number of conditions. However, you will notice that most states at least screen for the conditions

**State Screening Information**

Not every state screens for every condition. Use this tool to see what conditions your state screens for.

- Select State -

[Learn more about State Screening](#)

## 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

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## 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](#)

**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

Thalia Wood, MPH  
 Children's Health Unit Manager  
 Section of Women's, Children's and Family Health  
 3601 C Street, Suite 322  
 Anchorage, AK 99503-5923  
 (907) 269-3499  
 thalia.wood@alaska.gov

## 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 <b>video vignette</b> 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 <b>childbirth educators</b> 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 <b>NBS information needs</b> , via electronic surveys/questionnaires at the Hawai'i Baby Expo and <b>Hawai'i WIC clinics</b> ; Conduct focus groups to evaluate the BabysFirstTest.org website.
APHL 	Develop a <b>video detailing the NBS process at a state public health laboratory</b> 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

- **Sharon Terry**, Principal Investigator, [sterry@geneticalliance.org](mailto:sterry@geneticalliance.org)
- **Natasha Bonhomme**, Project Director, [nbonhomme@geneticalliance.org](mailto:nbonhomme@geneticalliance.org)
- **Elizabeth Stark**, Maternal & Child Health Manager, [estark@geneticalliance.org](mailto:estark@geneticalliance.org)
- **Tara Biagi**, Maternal & Child Health Coordinator, [tbiagi@geneticalliance.org](mailto:tbiagi@geneticalliance.org)
- **Scott McDaniel**, Web Projects Director, [smcdaniel@geneticalliance.org](mailto:smcdaniel@geneticalliance.org)
- **Mark Petruniak**, New Media Coordinator, [mpetruniak@geneticalliance.org](mailto:mpetruniak@geneticalliance.org)

## www.geneticalliance.org

The screenshot shows the homepage of Genetic Alliance. At the top, there is a navigation bar with links for HOME, JOIN, SIGN IN, and DONATE. Below this is a search bar and a secondary navigation menu with links for About Us, Resources & Services, Programs, Policy, Publications, Events, Resource Repository, and 25th. The main content area features a large orange banner for the 25th Anniversary Celebration, which includes a diagram of a wheel with labels  $\alpha$  and  $b$ . The banner text reads "Register Now! Genetic Alliance 25th Anniversary Celebration" and "Join us for Genetic Alliance's 25th Anniversary Celebration! September 22, 2011". Below the banner, there are three columns of content: "Follow @geneticalliance" with two tweets, "Network" with a "Meet Your Neighbors" section and a logo, and "Policy" with a link to "Money for Integrating Breast Cancer Genomics".

# www.geneticalliance.org/resources

**Genetic Alliance Resources and Services**

Genetic Alliance is proud to provide a range of resources and services that benefit both individuals and organizations. We welcome and encourage your involvement: listen to webinars, create and edit entries in WikiGenetics and WikiAdvocacy, participate in the Advocates Partnership Program, add your organization to Disease InfoSearch, and more.

Individuals and organizations can utilize our resources to:

- [Stay Informed](#)
- [Engage and Participate](#)
- [Organization Resources](#)

Some of our resources are tailored specifically for organizations:

- [Organization Resources](#)

We also have a [Community Job Board](#) where organizations can post job openings and individuals can find new and exciting opportunities for employment.

[Subscribe](#)

**Stay Informed**

**Announcements**

Periodically, Genetic Alliance will alert you to important action items, announcements, and deadlines, including Genetic Alliance-specific material as well as information from the genetics, health, and advocacy communities. Some weeks there will be no emails; other weeks one or more might be sent to the list. This listserv includes the Advocacy in Genetics newsletter, which is distributed a few times a year with updates on Genetic Alliance activities.

**Newborn Screening Newsletter**

This quarterly newsletter provides updates on the advancement of Genetic Alliance newborn screening initiatives, current newborn screening news, and new opportunities to engage in newborn

# www.wikiadvocacy.org

**Main Page**

**Welcome to WikiAdvocacy** [edit]

WikiAdvocacy is a free, reader-built guide, as well as a community for advocacy. It covers every aspect of founding and growing an advocacy organization from fundraising to detailed explanations of issues, skills, and the elements of creating a registry and samples repository.

If this is your first time visiting WikiAdvocacy, we recommend reading [About WikiAdvocacy](#) and [How to Get Started](#). We also recommend checking out the [community portal](#) and [help](#) pages.

[I](#) [About WikiAdvocacy](#) | [How to Get Started](#) | [Community Portal](#) | [Help](#) | [How to: Create a New Wiki Page](#) | [How to post a file on WikiAdvocacy](#) |

**Introduction**

- Defining Our Terms
- The Power of Advocacy Organizations
- Why Go There?
- How to Use This Guide
- History of Advocacy Organizations and Genetic Alliance
- The Kitchen Table is a Good Place to Start
- Genetic Alliance

**Organizational Assessment**

- Determine Goals
- Characterize Condition
- Characterize Resources
- Compare Goals and Resources, with the Characteristics of the Condition
- Considering Starting a Support Group for a Condition that Already Has One?

**Organization Development: Organizational Structure**

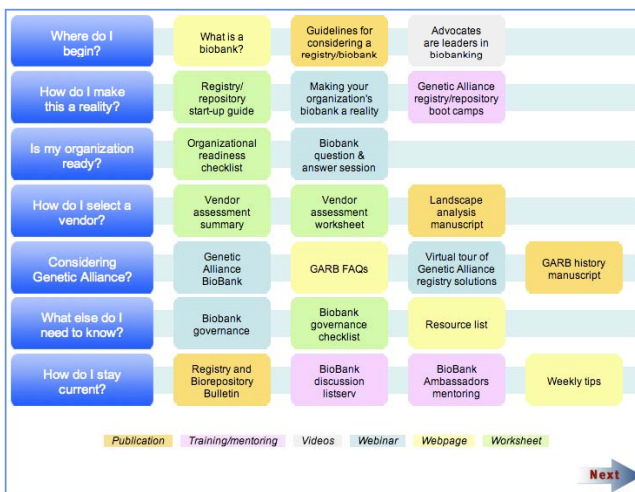
- Advisory Boards
- Bylaws and Articles
- Governance Board
- Ensuring Cultural Competence
- Finding a Lawyer
- Insurance and Policies

**Organization Development: Resources for Development**

- Becoming the Organization You Imagine
- Building a Website
- Charity Rating Listings
- Conference Call Services
- Donations
- Events

www.biobank.org

Please [click here](#) to view a PDF description of the GARB Toolbox.



Thank you!

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 lhorn@geneticalliance.org

