Baby’s First Test: What is offered, Who we Reached, What we’ve Learned

Advisory Committee on Heritable Disorders in Newborns and Children

November 1, 2018
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“Why do you need to educate about newborn screening? It just happens – parents don’t have to do anything or ask for it.”

“Thankfully, we were quickly educated about MCADD by both our pediatrician and some incredible genetic and metabolic specialists at Children’s Hospital… He is going to be fine because everyone knows how his body works differently and can factor that knowledge into his care.”

– Kay Kelly, 2013 Consumer Task Force member & mom to 2 boys, one of whom has MCADD
Baby’s First Test is a national newborn screening resource center (known as the Clearinghouse until Aug 2018). Baby’s First Test informs and supports millions of families and healthcare professionals throughout the newborn screening experience.
BabysFirstTest.org: Primary Platform for Increasing Knowledge & Awareness
BabysFirstTest.org since 2011...

2.8 Million Visitors

3.4 Million Sessions

5.2 Million Hits

1:29 average session duration

1.64 pages per session

88% unique user vs 12% returning user

~86% of users are of reproductive age (18 – 44)
Looking to Learn about Newborn Screening in Your State?

(There's An App For That)

Search State Information

Search Condition Information

Save Your Searches

Download for Free

Available on the App Store

GET IT ON Google play
On July 2, 2018 Spinal Muscular Atrophy was added to the RUSP, bringing the total number of conditions on the list to 35.
Newborn Screening Education and Training Resources

Looking for educational materials about newborn screening? Starting in September 2016, Baby’s First Test will be featuring fact sheets, videos, promising practices, and educational tools from states and organizations across the United States. Simply filter by resource type or audience, or search by keyword, to find resources that match your interest.

Interested in adding your educational resource, or not finding what you are looking for? Email resources@babysfirsttest.org for more information.

FILTER BY: Clear Filters

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<thead>
<tr>
<th>Type</th>
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About Prenatal & Newborn Screening

Prenatal Screenings ensure you and your baby are on track for a healthy pregnancy. They also prepare parents for potential health conditions and treatments before birth.

Newborn Screening is a state public health program that tests for serious and treatable conditions. Babies who test positive for treatable conditions are able to start treatment before harmful effects occur.

Blood Test
A small blood sample is taken from the baby’s heel, placed on a newborn screening card, and sent to the state laboratory for analysis.

Hearing Screens
 Determines if the ear and auditory brain stem respond to sound. No response can indicate hearing loss.

Pulse Oximetry Test
A sensor measures oxygen in the blood and can detect Critical Congenital Heart Disease (CCHD).

Why is screening so important?
Babies who appear healthy and come from healthy families can still have serious medical conditions. Newborn screening helps health professionals identify and treat conditions before they make a baby sick. Most babies identified at birth are treated early and grow up healthy.

Nearly 4 million babies are born every year in the United States

More than 1 in 300 newborns have a condition detectable through newborn screening.

About 1 in 125 newborns have a Congenital Heart Defect.

Newborn Screening is one of the greatest public health achievements of the 20th century.

Most states screen for 29 out of 34 recommended health conditions.

24-48 HOURS
All newborns should be screened between 24-48 hours after birth.

According to the Centers for Disease Control and Prevention

One Mother’s Perspective

“Newborn screening saved my son’s life. Although he appeared perfectly healthy and our family has no history of any disorders, his screening came back positive for a metabolic condition called MCADD. Thanks to the information we gained through his newborn screening, he is a perfectly healthy little boy and we know how to care for him to keep him that way.

I urge all new parents to learn about the life-saving potential of newborn screening and to thank the hospital staff who perform this very important test to ensure the health and safety of your newborn.”

- A Grateful Mother in Colorado
Spanish.BabysFirstTest.org

- **Launched in 2015**
- **Ongoing process to update site to be reflective of feedback and our audience:** adaptation, not translation

¿Pruebas de Detección en Recién Nacidos?

Muchos padres no conocen sobre las condiciones incluidas en las pruebas de detección, o el hecho que varían de estado.
Spanish.BabysFirstTest.org

- 60.8% Parent/family member
- 33.0% Health professional
- 3.2% State NBS program
- 3.1% Industry representative
- 8.3% Advocate

*1,162 responses, current as of April 25, 2018
Educational Materials in Spanish

- Housed on Baby’s First Test Resource Center
- Available for order
Usability & Experience with BabysFirstTest.org
Evaluating Baby’s First Test

**Methods**

1. Google Analytics

2. User Survey

3. Evaluation with RTI
   - New & Expecting Parents
   - Healthcare Professionals
   - Partners

**Buckets of Evaluation**

- Reach of BabysFirstTest.org
- User Engagement
- User Knowledge & Awareness
- Partnerships
Website Evaluation with Parents
Methods and Conceptual Model

- 777 women and men planning a pregnancy or currently pregnant or with a pregnant partner

**Condition:** Control vs. BFT web page

**Message Responses:**
- Perceived quality
- Emotional response

**Knowledge of NBS**
- Self-efficacy to
  - Make informed decisions about NBS
  - Navigate the NBS system
  - Talk to doctor

**Intention to**
- Share information with friends and family
- Talk to a doctor
- Recommend web page
- Return to the web page for more information

**KEY TO VARIABLES**

- Individual characteristics measured before web page exposure
- Mediators measured after web page exposure
- Outcomes measured after web page exposure
Awareness of Newborn Screening

- Prior to viewing any stimuli, **two-thirds of the participants** (66%) reported having heard of the term “newborn screening.”

- When asked to identify the accurate definition of “newborn screening” from three statements, only about **one-third of the participants** chose the correct definition (36%).
The knowledge score for each group is the mean number of correct responses out of a possible 13.

Statistically significant difference between BFT and control group (<0.05)
Self-Efficacy

I feel more confident in my ability to make informed decisions about newborn health.**

I feel more confident in my ability to talk to my doctor about issues around newborn health.**

I feel more confident in my ability to find information about newborn screening.**

I feel more confident in my ability to select healthy foods for someone who is pregnant.**

I feel more confident in my ability to support a healthy pregnancy for me or my partner.*

I feel more confident in my ability to avoid unhealthy foods during pregnancy for me or my partner.**

Note: * indicates $p<0.01$; ** indicates $p<0.0001$
Implications

**Rigorous design:** an experimental design allowed us to thoroughly answer the research question: *does BFT increase knowledge about NBS among parents/families?*

**NBS knowledge:** This evaluation went beyond typical website evaluation measures to concretely assess changes in knowledge, self-efficacy, and behavioral intentions.

**Effective Tool:** Results from this evaluation suggest that individuals in the perinatal period do not know what NBS is, but exposure to even one web page on the babysfirsttest.org significantly increased their levels of knowledge about NBS.
Healthcare Professional Usability Testing
# Methods

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User Needs

- Communication with parents about **newborn screening is not** a priority topic for these HCPs.
- Participants reported being **comfortable talking about newborn screening** in general.
- HCPs may need **extra information about rare conditions or in cases of abnormal test results**.
- Participants were **not necessarily seeking out** a resource like this.
- None of the participants had ever seen BabysFirstTest.org before.
- **Most HCPs found it very useful** that this information is available.
- Participants said an **ideal website would educate both themselves and parents** about NBS.
Website Perceptions

- When looking at the Baby’s First Test homepage, HCPs thought the purpose of the website was:
  1. To educate and provide expectant parents with comprehensive information about NBS
  2. To provide HCPs with information about conditions screened through NBS

- Participants saw expectant parents as the primary target of the site’s content and language

- They also reported that the site contained information that would help them do their job.

- All of the participants had a positive impression of the website content, commonly describing the content as “very informative” and “comprehensive” or “thorough.”
Outcomes

- **About half of the participants reported learning something new**, with the main value of the website being that that they would:
  - Share and review information from the website with parents
  - Direct parents to information on the website
  - Provide printed materials to parents

- **Participants mentioned a range of reasons for which they would use the website**, including:
  - Returning to the website to learn more upon receipt of an abnormal test result for a patient
  - Providing useful resources to parents of newborns
  - Using the website to self-educate about tests and conditions.

- The majority of participants enthusiastically indicated that they are **highly likely to visit the website again**.
Implications

- HCPs find the site useful, but are unaware of the site.
  - Promote the BabysFirstTest.org to HCPs through channels that reach them.
  - Provide concrete next steps on abnormal test results, possibly via a separate tab for providers that combines all information about abnormal results in one place.
  - Increase content that facilitates connections to support networks for more of the conditions.
Partner Evaluation
Evaluation Questions

- How many and what types of partnerships have been formed?
- What have been the benefits/value-added to partnering with federal and non-federal organizations?
- What has resulted from these partnerships?
Methods

Partner Inventory:
- Categorized partners according to key domains, such as type of organization and stage of partnership in an Excel database.

Partner Survey
- Selected 15 partners that represented key audiences for BabysFirstTest.org.
- Conducted web-based survey.
Number and Types of Partner Organizations

- By the final year of the program, *Baby’s First Test* partnered with 59 organizations.
Partner Roles and Activities

- Website Content Contribution/Link: 34
- Dissemination (Link to BFT): 26
- Education (Webinars, Trainings, Workshops): 22
- Capacity-Building and Technical Assistance: 11
- Program Evaluation: 1
Value of Partnership

- When asked what value, if any, this partnership brings to their work, almost every Partner Survey participant emphasized the value of their access to knowledge, information, or education developed and provided by Baby’s First Test.

- Many partners described the ways in which access to Baby’s First Test increases their capacity.

“Baby’s First Test provides evaluated and robust educational materials and resources that we often do not have the time or expertise to create ourselves. Additionally, Baby’s First Test has raised the bar for programs in terms of their educational outreach... I cannot stress enough the value of this partnership in improving our overall program and its relationship to our stakeholders, including the public.”
Benefits of Partnership

“Compared to other organizations we partner with, Baby’s First Test is a valuable partner.”

- Agree: 14%
- Strongly Agree: 79%
- Neither Agree nor Disagree: 7%

“The partnership with Baby’s First Test is essential to my organization/agency accomplishing its education and outreach goals.”

- Neither Agree nor Disagree: 21%
- Agree: 29%
- Strongly Agree: 50%
Future Partnership Plans

- **Ease of partnership:**
  - Essentially all of partners regarded partnering with as easy (n=3) or very easy (n=10).

- **Future Partnerships Likely:**
  - All Partner Survey respondents reported that is it either very likely (n=12) or likely (n=2) that they will continue to partner with Baby’s First Test next year.
  - The majority of participants consider activities related to continued external funding for NBS education/outreach to be important (36%) or very important (50%).

- **Recommendations:**
  - Expand the number of partnerships with advocacy/health promotion groups, educators, health care providers, and state/local departments of health to further extend reach;
  - Prioritize activities related to continued external funding for NBS education/outreach; and
  - Assess which partners feel strongly about developing written goals for the partnership and a more formal partnership agreement and implement accordingly.
Lessons Learned
What We’ve Done

- Responsive Website(s)
- Mobile App
- Share & Collect Family Experiences
- Trained Families
- Educational Resources
- Interactive Map & Forum
- Ask an Expert
- Social Media Campaigns
- Webinars
- Newsletters
- Animated Videos
- Billboards (yes, really)
- Awareness Building (Google Adwords, BabyCenter)

- Exhibits/Conferences
- Presentations
- Hosted Meetings
- Focus Groups
- Needs Assessments
- Message Testing
- Trainings to State Advisory Groups
- Evaluation
- Partnership Building
- Technical Support
- Review Educational Campaigns
- Create & Co Brand Materials

And much, much more…
Continuum of NBS Information Touchpoints

THESE ARE NOT **SYNONYMOUS**!

- **Awareness**: Exposure to information
- **Education**: Imparting fundamental knowledge and tools that can be used to grow and expand the concept
- **Training**: Imparting “how to” knowledge
- **Engagement**: Bidirectional process of collaboration

"How incredibly grateful I am for the materials you've provided me with--you've made doing what I do so much easier. From the bottom of my heart, thank you!!"
Ask an Expert

- General NBS Questions: 28%
- Interpretation of Results and Clinical Follow-up: 27%
- Access to Results or NBS Timing: 9%
- NBS Interest or Advocacy: 4%
- [CATEGORY NAME]: 1%
- Non-NBS Questions: 27%

*2016-2017 Data*
What Do They Want To Know?

Parents

1. **The Why**
   - Importance of newborn screening

2. **The What**
   - Screening procedures

3. **The What Now?**
   - Copy of results
   - Talk to your health professional

HCP

1. **The Why**
   - Importance of newborn screening

2. **The What**
   - Screening procedures
   - State requirements
   - Newborn screening conditions

3. **The What Now?**
   - Communication tools
     - Messaging
     - Responding to Results
   - Resources
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  - Beth Tarini, MD, MS
  - Stacy Hines-Dowell, DNP, AGN-BC
  - Aaron Goldenberg, PhD, MPH

- **Genetic Alliance**

- **MCHB, Health Resources and Services Administration**

Email: [Natasha@BabysFirstTest.org](mailto:Natasha@BabysFirstTest.org)
Phone: 202.966.5557 x216
“At first, I was scared and I cried, but after months of testing and careful follow-up, we now know what to look for, when and what Tristan should be eating since his body can’t fully process protein. To be honest, if it wasn’t for his newborn screening, I don’t know where we would be today. I’m grateful. Tristan is a super happy, healthy boy.”

Tristan was born Jan. 21, 2016 with Methylmalonic Acidemia Minus (Mut-). Story shared by Tristan’s mother, Christine Camacho.